

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 president@co-parkinson.org
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Janet Adams, Beth Clarke,

Janet Adams, Beth Clarke, Gene Clarke, Jack Dashosh, Pat Dashosh, John Farley, Carole Henrichsen, Steve Locke, Paul Mackendrick, Dave Moross, Mary Sauvain, Rich Sauvain

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Educational Outreach: Jill Reid
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Photographer: Vacant
Lending Locker Coordinator:

Rich Sauvain

Main Dish Coordinator:

Bill Hicks 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

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

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, May 14th – 10:00 am – 1:30 pm

We will be Zooming and 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: Results of the CPF Phenomenological Study of Wives Caring for

their Husbands with Parkinson's Disease

Speaker: Dawn White, PhD, MS, RT(R)



Dr. White is currently working towards a Doctor of Health Science with a Global Health concentration at A.T. Still University, with a graduation date of May 27, 2022. She is an alumnus of Walden University and holds a Ph.D. in Psychology with a specialization in Teaching of Psychology, a Master's of Science in Psychology. She received a Bachelors in Psychology from Old Dominion University, and an Associated degree in Radiology

from Tidewater Community College. She has been employed with Sentara Leigh Hospital for over 30 years in the field of Radiology.

Currently, Dr. White participates as a qualitative researcher with the Colorado Parkinson Foundation to determine if the Ketogenic diet will help reduce inflammation, increase quality-of-life, and increase healthy living for Parkinson's patients (published Feb 2022). Additionally, she is involved in a research study with Parkinson's disease caregivers and finding ways to assist them while they assist their loved ones. Prior research includes reducing workplace bullying and increasing resilience within the medical field.

In her personal life, Dr. White and her husband, Tim, have been married for 16 years. Their close-knit family includes two children, six grandchildren, and two spoiled English Labs. Her family is important to her, and they gather for family dinner each Tuesday.

The May Potluck Main Dish – A Brunch Theme — PANCAKES WILL BE PROVIDED —

Side dishes to bring: Egg Dishes, Hashbrowns, Breakfast Meats, etc.

If you would like to sign up to be one of the providers of a main dish or a side dish/dessert for the May meeting, you can contact Bill Hicks at or potluck@co-parkinson.org, no later than Wednesday, May 11th 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



Back in the mid-1990's, the Jeanne Taylor Parkinson's Support Group published a recipe book of potluck favorites. We called it Shakin' and Bakin' with Parkinson's. (To prove to you how long ago we published it, Julie's and my recipes are under our maiden names! Julie and Ric were married in 1997.) When Sherry Whitaker volunteered recently to put together a similar recipe book of for the Colorado Springs Parkinson's Support Group, Julie and I fondly remembered that old one and thought that we could just add your favorites to the old favorites and republish it! I had an extra copy of Shakin' and Bakin' that Julie gave Sherry, who enthusiastically agreed to the modified idea.

There are very few of the original contributors to Shakin' and Bakin' still with the support group, so it's definitely long overdue for a make-over (like the make-over we gave our group when we changed its name to the Colorado Springs Parkinson's Support Group) that has your fresh ideas. As a bonus, those of you who weren't with the group back then can enjoy the "oldies but goodies" (you know how cooks are: they always

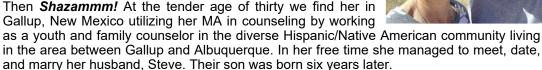
provide their best recipes for such projects, recipes that stand the test of time).

In the last couple of years, we've learned a lot about the benefits of a low-carb/healthy fat (keto) diet for people who have Parkinson's so you may think we only want keto recipes. Nope! We want all your favorites! And if your favorite potluck recipes aren't keto, they theoretically could be made keto by a few substitutions. Included in this version of Shakin' and Bakin will be a list of ingredient substitutions that can turn almost any recipe in the book into a keto dish. That way, we'll get the best of both worlds.

The recipe book will have six sections: Appetizers, Breads, Salads, Side Dishes, Main Dishes, and Desserts. Send as many recipes that you would like to be included and that fit these categories to Sherry at project@co-parkinson.org. She will then create the new Shakin' and Bakin' with Parkinson's, Version 2.0. Good eatin'!

Getting To Know You: Lynn and Steve Kozeliski

If VARIETY is truly the SPICE of LIFE - Then getting to know Lynn Kozeliski will indeed be a TANGY adventure. She has bundled a lot of education, training, diverse working and business experience into her young life. Lynn was born and raised in the Buffalo, New York area. Her work there ran the gamut from supermarket clerk and house cleaner to head hunter for a business that provided engineers to government contractors. Along the way she accumulated credentials in paralegal/legal studies.



Lynn enjoyed her time as a "stay at home" mom. However, by 2006 she and Steve realized that in order to find better schools for their son they needed to relocate. They moved to Colorado Springs and bought out an Ice Cream Shop and became owners of "Cold Stone Creamery".

Enter Mr. Parkinson's bringing even more variety and diversity into Lynn's life. Her experiences, symptoms, and treatment became another focus for she and her family. At this point in our "story", it's appropriate to continue as a First Person narrative. To facilitate that, please introduce yourself to Lynn and GET to KNOW her and the REST of HER story.

Prodromal PD and RBD: What is the Link?

By Clinical Science via Working Parkinson's Connection

"RBD is caused by loss of a singing,

making normal system that keeps us movements, punching, etc.) tually in early stages of Parkparalyzed during our REM this is different than the com- inson's or other closely relatsleep stage (when dreams mon sleep walking or sleep ed conditions (namely Deare most vivid) - this system talking of children and young mentia with Lewy bodies or prevents us from moving dur- adults; it's something that Multiple System Atrophy). It ing our dreams. In RBS, generally starts as people is, in fact, the Parkinson's when the system breaks age (50's or older). Over the degeneration itself that is down, people will 'act out' last decade or so, we have causing the system to break their dreams (talking loudly, learned that the large majori- down."

running ty of those with RBS are ac-



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!





All worldwide charities have received

\$377,951,346.33

as of March 2022

April 9, 2022 Program Review

Wealth Preservation & Planning for Long Term Care Presented by: Kim Searles, Beneficent – LTC Consulting Group

Kim's brother, Adam Searles, is a person with Parkinson's, which makes Kim even more passionate about sharing long-term care Medicaid to help other people.

- Do you have Parkinson's? Do you personally need support?
- Are you a caregiver for someone with Parkinson's? How can a caregiver get a break?
- Caregiving is an honor, but it comes with stress, learn about programs that will support caregivers.
- Caregivers are often overworked, and some give up their careers to support their loves ones.
- Learn how programs can pay a caregiver or care facility if that assistance is needed.

Strategies to pay for the high cost of care:

- We help caregivers tap into programs to protect family's cash and avoid spend-down.
- Beneficent connects seniors and disables individuals to funds that pay for the high-quality care.
- We have 100% application success rate.
- Beneficent has been privileged to successfully assist thousands of families and individuals through asset preservation while coping with lone-term care costs.

Generational Testimony:

- Stacy's parents believed they had to "spend-down."
- They lost their grandmother's home.
- Do you have something you want to keep for the next generation?

VA Aid + Attendance and Long-term Care Medicaid – financial programs that help pay for long-term care including in-home care, assisted living, memory care, and full skilled care:

- In the state of Colorado, families are searching for ways to cover the high costs of long-term care.
- Certified Medicaid Planners represent clients that have been denied due to common application mistakes. Certified Medicaid Planners can avoid those common errors.
- It is important to understand the Department of Health Care Policy + Finance (HCPF) policies, guidelines, and rules around Long-term Care Medicaid programs.
- Families with the correct information can obtain benefits.

Presentation Overview:

- Understanding payment for: private pay facilities, nonmedical companies, and placement agencies.
- Understand a case study.
- Creating clarity around how the process works.
- Identifying clients who may benefit for these state and federal programs.

How to Qualify for Long-term Care Medicaid or VA Aid + Attendance?

- Based on the department of human services information, 70% of applicants that apply for long-term care on their own are denied due to inaccurate information and incomplete filing.
- It is important to know the rules, so the "spend-down" process is completed inside of the guideline for qualification.
- Many families are told they will not qualify for state and federal programs because they have too much income or too many assets. That is not always true!

VA Aid + Attendance Program 2022 Veterans Benefits: Monthly Pension Rates

\$138,489 in assets, excluding home & car and still qualify!

Single Veteran	\$2,050			
Two Married Veterans	\$3,261			
Surviving Spouse	\$1,318			
One Married Veteran w/ Spouse	\$2,431			

- VA Aid + Attendance allows for eligible veterans or their spouses to afford the care they need without any payback or reclaim tot the government.
- The funds are tax free. VA Aid + Attendance can be used for in-home care, assisted living, full skilled nursing care and monthly prescription premiums.
- The Vet need to have served 90 days of active duty with at least one day during wartime and must be considered "totally disables" (need help with 2 activities of daily living).

Colorado Health First Program – Colorado Long-Term Care Medicaid will pay for: in-home care, assisted living, memory care, full skilled nursing.

Income Trusts are used when a Medicaid applicant has <u>too</u> <u>much income</u> to qualify for Medicaid but not enough to pay for long-term care.

"Spend Down" funds are kept safe:

- Clients set aside "spend down" money for a set period of time to privately pay for In-Home Care or to stay in a facility.
- No family members have access to these funds so it grantees private pay funds to pay for care.

Colorado Health First Program

Income Trust Gross Income Cap = CO State Regions					
Region I	\$9,500				
Region II	\$8,627				
Region III	\$8,166				
Region IV	\$8,145				

- Qualification Requirements:
- Must be over the age of 65, blind or disabled adult
- Income cap of \$2,523 unless an Income Trust is used
- Asset limit of \$137,400 for married couples
- Asset limit of \$2000 for single people
- If you don't meet those requirements there are strategies to access benefits
- Help with 2 activities of daily living
 - Following the guidelines carefully and having an experienced planner can ensure that the maximum amount of benefit is derived with the least amount of erosion of personal assets.

Recipe of the Month: Two-Cheese Sausage Pizza | Serves 4

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 lb sweet Italian

1 T olive oil

turkey sausage

2 C sliced mushrooms

1 small red onion. thinly sliced 1 small green bell pepper,

1/4 t salt

1/4 t pepper ½ C pizza sauce cut into thin strips 2 T tomato paste

1/4 t dried oregano

1/2 C shredded Parmesan cheese 1 C (4 oz) shredded Mozzarella cheese 8 pitted black olives

Preheat oven to 400 degrees. Remove sausage from casings. Pat into 9" glass pie plate. Bake 10 minutes or until sausage is firm. Remove from oven and carefully pour off fat. Set aside.

Heat oil in large skillet. Add mushrooms, onion, bell pepper, salt, oregano and black pepper. Cook and stir over medium-high heat 10 minutes or until vegetables are very tender.

Combine pizza sauce and tomato paste in small bowl; stir until well blended. Spread over sausage crust. Spoon half of vegetables over tomato sauce, sprinkle with parmesan and mozzarella cheeses. Top with remaining vegetables. Sprinkle with olives. Bake 8 to 10 minutes or until cheese melts.

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 Colo Spgs, 80918.

> Contact Brenda Hicks at or

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

Syble Krafft at

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

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

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

Swallowina

- Neuromuscular Electrical Stimulation

- 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.

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.

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



Janet Adams **Owen Briggs** Pat Bush Sue Coen Anita Damon John Fly Joan Foutz

Carol Gugat Ross Huddleson Judy Ireland Don Jaeger Donna Malmgren Carol Morris Jaros Murphy

Lu Ann Nickelson Eileen O'Reilly Katrina Rochón Sonya Shannon **Beverly Wells** Hope Winkler

May Executive Committee Meetings

May 17th 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.

June Newsletter Input Deadline: May 18th Call or e-mail Julie at:

db_mgr@co-parkinson.org.

LENDING LOCKED

I	LENDING LOCKER	bed carie	3	TOILET ATTT ASSIST	ı	Shower periones	9
I	INVENTORY Note: A stair chair lift	Bed pan	1	Lift-ware tremor compensating utensils	1 set	Toilet seats	3
I	system has been donated to us.	Bedside toilets	6	Crutches	2 sets	Transport chairs	3
I	It's a seat on a rail that takes you up and down a staircase.	Canes	7	Back brace	1	Tub rail	2
I	This one is for a 14 step or less	Exercise bike	1	Bed rails	1	U-step	4
I	straight staircase with no turns. If you would like to borrow any of the	Double exercise pedals	1	Sock helper	2	Walkers with wheels and a seat	11
I	equipment listed here, please contact:	Lift chairs	2	Stair chair rail system	1	Wheelchairs	7
I	Rich Sauvain at .	Swivel seat	1	Pick-up assist	6	3-wheeled walker	1

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.

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.

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.

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

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

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

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

Tai Chi Improves Motor Function in Early-stage Parkinson's: Study

By Patricia Inacio, PhD – Parkinson's New Today, 4/15/22

proved gait and balance in earlystage Parkinson's disease patients, improving both inflammation and metabolism as well as brain function, according to a recent study.

The study, "Mechanisms of motor symptom improvement by longterm Tai Chi training in Parkinson's disease patients," was published in Translational Neurodegeneration.

Tai chi combines continuous and gentle body movements with breathing control to improve muscle strength, balance, and motor control. Clinical evidence has suggested that practicing it for six months can reduce moto symptoms and improve quality of life for those with Parkinson's disease.

However, due to the progressive nature of Parkinson's, it's not know if there are any long-term therapeutic benefits to practicing it.

A team led by researchers in China conducted a clinical trial to assess the long-term effects – over one year - of tai chi training on Parkinson's motor symptoms. The trial was done as part of a philanthropic project call "Tai Chi Adjuvant Therapy for Parkinson's Disease," jointly launched by Fosun Foundation, Sino Taiji and the Neurology Department of Rujin Hospital.

The project has provided free

Practicing tai chi for a year im- courses for 445 patients with Park- Compared to controls, those who ing and clearing toxic reactive speinson's disease and will continue to carry out charitable tai chi courses for Parkinson's patients across

> In total, 95 patients with earlystage Parkinson's were randomly assigned to one of three groups a tai chi group (32 patients, mean age 62.7 years), a brisk walking group (31 patients, mean age 61.9 years) and a non-exercise group that served as a control (32 patients, mean age 61.9).

> Motor symptoms were evaluated at the trial's start (baseline) and then again at six and 12 months using the Berg Balance Scale (BBS), the Unified Parkinson's disease rating scale (IPDRS), the Time Up and Go test (TUG) and spatial 3D gait (walking) analysis.

> The TUG test evaluates the time taken to stand up from an armchair, walk three meters, turn, walk back, and sit down.

> The six-month and 12-month follow ups were completed by 66 patients.

The results showed that, compared to the control group, patients in the tai chi group showed significant improvements in balance at six and 12 months of follow-up. It also was better than brisk walking at improving balance.

practiced tai chi showed significantly greater improvements in thought to play a key role in neuro-UPDRS scores after one year and in the TUG test at both follow-ups.

width were also observed at both follow-ups in those who practiced tai chi, compared to controls.

The tai chi group also showed It also resulted in increased levels greater improvements in step of HIP2, an enzyme that's been width, when compared to brisk linked to neurodegeneration, which walking.

Improved balance was correlated with enhanced visual network function and lower levels of interleukin-1-beta, a pro-inflammatory molecule. Improvements in motor scores were associated with enhanced default mode network function, a group of regions in the brain that are preferentially active "at rest" or not engaged in a specific mental task.

Along with lower levels of several inflammatory molecules, tai chi also led to a drop in different metabolites, including L-arginine, known for its role in oxidative stress. Metabolites are intermediate or end products, such as amino acids, organic acids, sugars, or lipids, that take part in or are produced as part of cellular metabo-

Oxidative stress, which is marked by the imbalance between produc-

cies that are harmful to cells, is degenerative diseases like Parkin-

Significant improvement in step Overall, tai chi altered the levels of several metabolites that were found to be related to changes in UPDRS scores.

> showed a tendency to be reduced in the control group. A previous study has found that lower levels of this enzyme cause motor function impairment in model of Parkinson's disease.

> The findings suggest that "longterm tai chi training improves motor function, especially gait and balance, in PD patients, the researchers wrote. "Enhanced brain network function, reduced inflammation, improved amino acid metabolism, energy metabolism and neurotransmitter metabolism, as well as decreased vulnerability to dopaminergic degeneration may be mechanisms underlying the effects of Tai Chi training."

> A separate study led by the same research team suggests tai chi training can delay the progression into Alzheimer's disease in people with mild cognitive impairment, a known disease risk factor.

Patient Screening Study for Potential Cell Therapy to Open Soon in US

By Mata Figueiredo, PhD - Parkinson's New Today, 4/14/22

During Parkinson's Awareness Month, **Aspen** said in a press release. Neuroscience will launch a patient screening study to potentially advance ANPD001, its experimental, personalized neuron replacement therapy for Parkinson's disease, into clinical trials.

Considered to be the first of its kind, the Trial-Ready Cohort Study will involve several screening sites in the U.S. they are expected to be announced throughout the spring.

It will serve as a preliminary step to support Aspen's filing of a new investigational drug (IND) application with the U.S. Food and Drug Administration seeking clearance to test ANPD001 in people, starting with a planned Phase 1/2a trial in Parkinson's patients.

The Trial-Ready Cohort Study is expected to provide information necessary to screen patients as potential candidates for the trial.

"This is an historic moment for patients and for the Aspen Neuroscience team, as we open out first screening study to expedite our investigation of iPSC-derived cell replacement thera-Parkinson's disease," for Damien McDevitt, PhD, Aspen's president and CEO,

"We are excited and very humbled to begin this next phase during Parkinson's Awareness Month," McDevitt said, adding that "this is a significant step forward for the patient community, for health care providers and the neuroscience field."

Parkinson's is characterized by the progressive loss of dopamine-producing, or dopaminergic, neurons in brain regions involved in voluntary movement, Dopamine is a major brain signaling molecule, and its defiance leads to the disease's hallmark motor symptoms.

By combining its expertise in stem cell biology, genetics, and neurology, Aspen developed ANPD001, the first potential, patient-derived neuron replacement therapy for Parkinson's.

The therapy involves collecting a patient's own skin cells and reprogramming them back to a stem cell-like state - then called induced pluripotent stem cells, or iPSCs - that give rise to almost every type of human cell, including dopamine-producing neurons.

iPSC-derived dopaminergic neurons are then

re-implanted in the patient, which is expected to ease or reverse Parkinson's motor symptoms. Before being transplanted, each patient's cells will be analyzed using artificial intelligence-based genetic tools.

Because these cells are derived from the patient, they can be re-implanted without the risk of being rejected, eliminating the need for immunosuppressive treatment, which can increase the risk of infections.

ANPD001 is being tested in IND-enabling preclinical studies, supported by the \$70 million Aspen raised in 2020 to advance both of its Parkinson's therapy candidates.

In addition to ANPD001, the company is developing ANPD002, a gene-editing therapy for Parkinson's associated with the most common mutation in the GBA gene - a major genetic risk factor the disease.

This treatment differs from ANPD001 in that it involves correcting the GBA mutation in patient-derived cells before their re-implantation. This approach is in its early stages of development, and proof-of=concept preclinical studies have yet to be complete.

...continued from Page 3: April 9, 2022 Program Review

Single Person Case Study – Shari was residing in a non-Medicaid Certified Assisted Living Facility. Shari declared a home, a vehicle, a life insurance policy, and case.

- Prior to application, Shari sold her property receiving \$193,000 in cash
- Shari's vehicle is exempt
- Shari's life insurance policy had a face value of \$25,000 and a cash value of \$2,000 which she transferred to a family member
- Shari gave a cash gift of \$170,000 to a family member
- The penalty assessed by the State was 20 months (based on cash gift and life insurance transfer)
- A spend down fund account was created for \$35,000 increasing her monthly income for 20 months

Outcome: Shari will continue to live in her current Assisted Living Facility during the penalty and has the money from the spend down account to pay for this care.

Married Couple Case Study – Case Study: Married Couple: Mark and Jill

What they have:

- Cash in the bank, \$61,000
- Investment Account, \$125,000
- Mark has a Roth IRA, \$140,000
- Jill has a Roth IRA, \$65,000
- Primary home in Colorado and two cars

Jill needs care in Assisted Living for advanced Dementia and has care costs of \$5000/month.

Jill can only have direct access to \$2,000 when we apply for Long-term care.

What Happens to Assets:

- Mark is assigned to the bank and investment accounts; he keeps his Roth by utilizing a spend down account to hold Roth investments and cash that is above the \$137K Community Spouse Resource limit under Mark's name.
- Their Colorado home is exempt and so are the cars.
- Jill's Roth is cashed out and cash held in with other investments.
- The State of Colorado will pay for Jill's care as of the date we file for Long-term care.
- 100% of their assets are available for Mark to use as he wishes in his lifetime. There are no penalties to transfer assets to a spouse.

Solutions – Almost every problem to long-term care costs has a solution. Proper education ensures eligibility can be obtained <u>and</u> assets preserved.

We are not attorneys; we do not practice law. We put benefits in place for long-term care.

Beneficent contact information:

- Phone: 719-645-8350
- Website: www.doinggoodforothers.com
- Email: info@doinggoodforothers.com
- Address: 665 Southpointe Court Ste #100
- Colorado Springs, CO 80906
- Schedule a FREE 60-minute Q&A at: calendly.com/doinggoodforothers

ABBV-951, Levodopa as Infusion, Seen as Similar to Intestinal Gel

By Steve Bryson, PhD - Parkinson's New Today, 3/31/22

ABBV-951, a continuous infusion formulation of levodopa/carbidopa, brought comparable levels of levodopa into the bloodstream of healthy volunteers as surgically implanted levodopa-carbidopa intestinal gel (LCIG), a Phase 1 study confirmed.

Because the delivery of doses can be tailored to a patient's needs, this alternative form of delivery – a portable pump allowing 24-hour, under-the-skin infusion of the medicine – may be an effective option for controlling Parkinson's symptoms and moto fluctuations in people with advanced disease, the researchers wrote.

The study, "Foslevodopa/foscarbidopa subcutaneous infusion maintains equivalent levodopa exposure to levodopa-carbidopa, intestinal gel delivered to the jejunum," was published in the journal *Parkinsonism & Related Disorders*.

Levodopa, a standard treatment, is a precursor of dopamine, the nerve signaling molecule that is abnormally low in Parkinson's patients. Levodopa is usually taken orally alongside **carbidopa**, a medicine that prevents the breakdown of levodopa before it reaches the brain.

But as Parkinson's progresses, the absorption of oral levodopa in the gut can vary, leading to fluctuations in the levels of levodopa in the blood-stream that reduce its effectiveness.

LCIG, sold as Duodopa or duopa, is formulation of levodopa and carbidopa developed by AbbVie and administered via a tube surgically inserted into the small intestines to minimize bloodstream fluctuations. LCIG is typically delivered over 16 hours during the day, and patients often take additional oral tablets of levodopa/carbidopa or other Parkinson's medications for symptoms that emerge during the night and in the morning.

ABBV-951, being developed by AbbVie, is a

subcutaneous (under-the-skin) formulation of foslevodopa and foscarbidopa, two prodrugs, metabolized into levodopa and carbidopa, that is administered through a continuous subcutaneous infusion via a portable pump. This delivery method has the potential to be as effective as LCIG without the need for surgery.

"Foslevodopa/foscarbidopa is intended for 24-hour continuous infusion to help manage night-time motor symptoms of Parkinson's disease as well as minimize morning 'off' symptoms," the researchers wrote.

In this Phase 1 study, scientists at AbbVie compared the therapeutic absorption of 24-hour foslevodopa/forcarbidopa delivery to 16-hour LCIG, plus two oral levodopa/carbidopa doses, in 25 healthy adults, ages 45 to 75. Participants were randomly assigned in equal numbers to either form of treatment delivery, then switched to the other delivery form.

Blood samples were collected before infusion and throughout each treatment regimen, with blood measured for levels of levodopa, carbidopa, foslevodopa, foscarbidopa, and 3-OMD, a metabolite of levodopa.

Analysis revealed that the difference in levodopa exposure was less than 8% between the two regimens, "well contained within the defined equivalence range," the scientists wrote. The two regimens differed little concerning short-term (up to 16 hours) or overall levodopa exposure.

The maximum level of levodopa achieved within a 16-hour window (hours 0 to 16) was lower for the foslevodopa/ofscarbidopa regimen than LCIG (605.6 vs 656.4 nanograms/mL), a ratio of 0.923.

Estimates for the overall maximum levodopa level were 658 nanograms/mL for the foslevodopa/foscarbidopa regimen and 1874 nanograms/

mL for LCIG plus two oral levodopa/carbidopa doses. The time to reach the maximum levels of 3-OMD was similar between the two regimens.

Between two and 16 hours, when both infusions were ongoing, bloodstream fluctuations in levodopa levels were lower for foslevodopa/foscarbidopa regimen compared with LCIG. From two to 24 hours, in comparison, the levodopa fluctuation was "considerably lower" than the LCIG plus two oral levodopa/carbidopa doses.

Continuous 24-hour infusion of foslevodopa/ foscarbidopa provided similar levodopa levels to LCIG infusion over the 16-hour interval, which were maintained throughout the night, the study noted.

Of the 25 adults that started the study, 20 completed both treatment regimens. Five left the study.

More treatment-related side effects were reported following foslevodopa/foscarbidopa infusion (79%) the LCIG delivery (20%), mainly driven by infusion-site reactions that included redness, swelling, and, less frequently, pain at the injection site. All were reported to be mild and to not cause anyone to discontinue the study.

"Foslevodopa/foscarbidopa subcutaneous infusion provides levodopa exposures comparable to LCIG throughout the day." The scientists concluded, with study findings showing that a continuous infusion of "foslevodopa / foscarbidopa achieves stable therapeutically relevant [levodopa] absorption."

While no new safety concerns were evident, "the importance of education in aseptic techniques and in the right application of the infusion set is crucial to guarantee an overall positive patient experience and minimize skin reaction," they added.

Colorado Parkinson Foundation, Inc.

1155 Kelly Johnson Blvd. Suite # 111 Colorado Springs, CO 80920

Parkinson's Perspective

MAY 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)

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.nwpf.org; michaelifoxfoundation.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