



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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Vacant

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potluck@co-parkinson.org

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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, June 1st – 10:00 am – 1:30 pm

We will NOT be Zooming OR 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.

June Program Topic: Break-Out Sessions

Moderators for the Parkinsonians: Kathleen Foster

and for the caregivers: Jill Reid & Julie Pfarrer

The Parkinsonians get together in one room and the caregivers in another to discuss their questions and concerns about their PD journey.

The meeting will be followed by a potluck

The June Potluck – Hot Dog Bar!

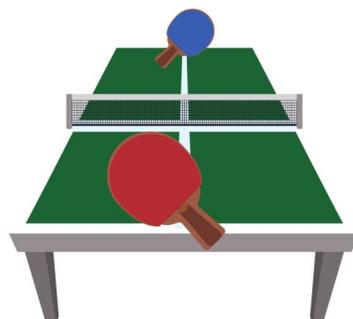
Bring a sealed package of hotdogs with buns (Bill & Brenda will cook them during the meeting) OR hot dog condiments, OR an appropriate side dish OR a dessert.

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, May 29th 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!

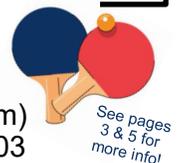
Mark Your Calendars — Neuropong Classes Start June 4th!!



When: Tuesdays & Thursdays

Time: 1:00 p.m. – 3:00 p.m.

Where: Downtown YMCA (the small gym)
207 North Nevada Avenue, CS, CO 80903



Do you have a connection with a company that might be willing to donate the cost of a ping pong table to our program?

If so, contact Julie Pfarrer at
treasurer@co-parkinson.org or at (719) 495-1853.

The President's Corner

| Jill Reid-Acting President, CPF & CSPSG



Let me start this month's President's Corner like I did last month's: "I don't know about you, but I'm really looking forward to" the June 4th start of NeuroPong at the downtown YMCA! For those of you who heard Dr. Barbera's presentation at the May meeting and/or at the November meeting, remember how excited we all were at the prospect of seeing the fantastic benefits of NeuroPong for ourselves. For those of you who missed those presentations, you need to be this excited, too! I encourage you to go to the Colorado Parkinson Foundation website (co-parkinson.org) and watch the November presentation; you'll find it on the Resources tab under Meeting Videos (by the time you read this, the video of the May presentation may be available). NeuroPong promises to enable those of you with Parkinson's to overcome stiffness, balance issues, cognitive issues, and movement issues while bringing fun and joy into your life! Can't get much better than that!

And now the possibility of NeuroPong has become a reality. Starting June 4, 2024, the NeuroPong classes will take place every Tuesday and Thursday from 1 pm to 3 pm at the downtown Y. We chose that YMCA because it is centrally located (our members live in Fountain and Monument and everywhere in between), it has an elevator to the second-floor gym where the classes will take place, and it

has a covered parking structure with plenty of handicapped parking spaces on the ground floor. To add to all these advantages, the classes are free (my husband's favorite price).

I will be working with Travis Lerma of the Pikes Peak YMCA to develop the registration process. We'll get that out to you as soon as it's ready.

Our hats off to Dr. Antonio Barbera, Travis Lerma and the Pikes Peak YMCA, NeuroPong trainer Larry Rose and Scott Preiss for bringing us this fantastic program.

The potluck at the May meeting was a huge success thanks to your wonderful response to the appeal I made at the April meeting and in the last newsletter. I pointed out to you the benefits of having potlucks and added that the potlucks were in jeopardy because we had been short of potluck dishes for several months and couldn't afford to keep buying food to cover the shortfalls we had been experiencing. The potlucks are a key part of our monthly meetings, a special time for socializing, getting to know each other, learning from each other, and expanding our social circles (key to longevity); such socialization is one of the main goals of this support group. We really need the potlucks to continue to be an integral part of each meeting. If you can afford to, please consider contributing main courses, side dishes, or desserts whenever you attend our meetings. But if you can't afford to, please don't hesitate to join us for the potlucks anyway so that you don't miss out on the benefits they provide.

This month's comedy is an oldie but goodie: *Life with Father*, starring Irene Dunne, William Powell, Martin Milner, Elizabeth Taylor, ZaSu Pitts, and Edmund Gwenn.

Michael J. Fox turns 63 on **June 9th!** Here are some fun facts to celebrate his birthday!

Did you Know?

Double the J?

Michael J. Fox's middle initial "J" isn't actually part of his birth name. He adopted it as a tribute to character actor Michael J. Pollard.

High School Dropout?

Believe it or not, Michael J. Fox actually dropped out of high school to pursue acting. Despite this, he's received honorary degrees from several universities!

Musical Talent?

Michael J. Fox is a really good self-taught guitar player. He even spent weeks practicing "Johnny B. Goode" for *Back to the Future!*

Royal Encounter:

At the world premiere of *Back to the Future*, Michael J. Fox found himself seated right next to Princess Diana!

*Happy Birthday
Michael J. Fox!*

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, send them in an email to Julie, our newsletter coordinator, db_mgr@co-parkinson.org.

Question: Can gastroparesis be a Parkinson's symptom? If so, how is it treated?

Answer: Gastroparesis [Gastro: relating to the stomach] is one of the gastrointestinal involvements of Parkinson's Disease. It is one of the symptoms of the autonomic impairment seen in PD. It is characterized by delayed stomach emptying of solid food in the absence of obstruction. Gastroparesis has been reported in nearly 45% of individuals with PD. The major symptoms include early satiety, excessive fullness after eating normal amounts of food, nausea, and rarely vomiting. The diagnosis can be made by appropriate tests that confirm delayed gastric emptying, although history in the presence of PD is usually enough to make a provisional diagnosis. Gastroparesis can lead to malnutrition and impairment of quality of life. There are no pharmacological treatments that I ever used in my former practice. Dietary modifications, including a low-fat diet [fats delay stomach emptying] with small frequent meals and liquid nutrients, can help with gastroparesis. If weight loss persists a referral to a Gastroenterologist should be considered. Interestingly, Deep Brain Stimulation usually improves Gastroparesis.

Program Review: May 4th, 2024

| by Secretary Patricia Beatty

Launching NeuroPong in Colorado Springs!

If you missed our May program, you missed a good one! The topic was "Launching NeuroPong in Colorado Springs!" presented by Dr. Antonio Barbera, MD... a passionate, knowledgeable, and dynamic speaker.

Until 2017 Dr. Barbera had a successful Obstetrics and Gynecology practice. Unfortunately, a positive diagnosis of Multiple Sclerosis (MS) forced him to give up his career. He lost the use of one leg but, over many months of determination and persistence, was able to learn to walk again. He also lost the use of his left arm and hand of which he has since regained the use.

Dr. Barbera said he always felt like there was an elephant sitting on his chest. One afternoon he joined a friend for a game of ping pong and was surprised to find that (after several games) the "elephant on his chest" left his chest and sat in the corner of the room! This was the motivating factor for him to begin his intensive study of the brain, how it relates to neurodegenerative conditions such as MS, dementia, and Parkinson's, and how ping pong (table tennis) could possibly relate.

He shared that the brain's overall size begins to shrink as you age, and the rate of shrinkage increases once you reach age 60. One part of the brain shrinks more than the rest: the hippocampus, the main functions of which involve human learning and memory. However, (and this is the good part) by challenging the brain with new things, hippocampus shrinkage can be slowed and even reversed! Our brains don't care if we do the same things, our brains need and respond to new things! He found that that's where the benefit of ping pong comes in... by constantly challenging the brain in a new way with every serve, return, and movement. He emphatically states that, "with 5 parts of the brain affected, ping pong is the #1 brain sport!"

Dr. Barbera developed his NeuroPong Program with the aim to improve both the motor and cognitive function of people living with neurodegenerative conditions which specifically includes Parkinson's. Several videos of people with either MS or Parkinson's were shown. We viewed people when they began the program and their movements were very limited and restricted. After participating in the NeuroPong Program for varying lengths of time (depending on the individual) we witnessed improvement in their balance, strength, movement, and cognition. It was amazing!

NOW FOR THE GOOD PART... TUESDAY, JUNE 4 a NeuroPong Program is starting at the Colorado Springs Downtown YMCA!

WHEN: Tuesday & Thursday

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

LOCATION: Downtown YMCA

207 North Nevada Avenue (in the Small Gym)

There is no cost and you do not have to be a member of the YMCA to participate!

YOU'RE IN GOOD HANDS

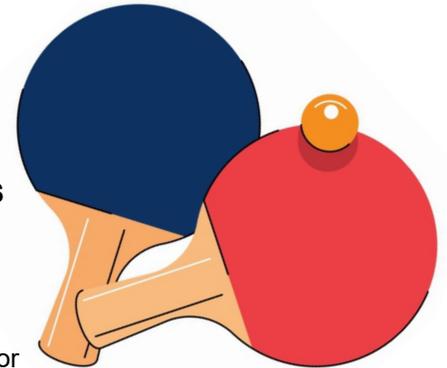
Scott Preiss, better known as "The Ping Pong Man" is a National level coach, has coached at the Olympics, and is currently administrator of the Ping Pong Club in Colorado Springs. His website states: "Many have said that Scott Preiss is the "Harlem Globetrotter" of Table Tennis with his electrifying display of his skill in the sport of Table Tennis. Scott has been dazzling audiences with table tennis comedy and trick shots for more than 30 years and has performed more than 3000 table tennis exhibitions and clinics worldwide. Scott was a former trainer for the US World Table Tennis Team, also a full time coach at the US Olympic Training Center in Colorado Springs and is one of the sport's greatest ambassadors." (www.pingpongman.com)

Larry Rose also has a long and successful career in ping pong. He is currently the administrator of the Pikes Peak Table Tennis Club in Colorado Springs. He, like Scott, has been in the sport for many years, both coaching and participating in tournaments.

Dr. Barbera proudly introduced both gentlemen to our group. Both have been trained by Dr. Barbera in the NeuroPong Program and are excited about how their collective expertise will benefit so many people with neurodegenerative conditions.

One last person was acknowledged: **Travis Lerma**. As Director of Healthcare Integration at the YMCA, he has led the way in making NeuroPong a reality at the Downtown YMCA. Ultimately, the goal of Dr. Barbera, Scott Preiss, Larry Rose and Travis Lerma is to provide physical, mental, and emotional improvement in everyone's life, no matter what their capabilities may be.

- For more information regarding the program at the Y, you may contact Travis Lerma at 719 495-5130 or tlerma@ppymca.org.
- For an in-depth highlight of Dr. Barbera's presentation, check out the December 2023/January 2024 issue of the Parkinson's Perspective.
- For a personal testimony as to the benefits of ping pong for a person with Parkinsons, check out the November 2023 issue of the Parkinson's Perspective.



SHEELS FLAG EXCHANGE

FRIDAY, JUNE 14TH

9:30 AM - 12:30 PM

COLORADO SPRINGS SCHEELS



Bring your faded or frayed American Flags to Scheels for a dignified disposal by the American Legion Post 2008.

They will replace your flag with a new 3'x5' nylon flag for free, *while supplies last!*

Thank You!

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

July & August Newsletter
Input Deadline: June 12th

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

CSPSG Executive Committee Meeting

June 4th 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. Gregory Ales, DO – Neurologist at CS Neurological Associates; (719) 473-3272

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

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

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

Dr. Brooke Heffernan, MD – Movement Disorders Fellow at UCHealth, Anschutz Medical Campus, (720)848-2080



Bob Adams
Donald Ader
Penny Austin
Deloit (Dee) Beatty
Linda Bresee
Mary Margaret Brummeler
Darrell Colwell
Carla Holland

Lynette Holland
Mike Koloski
Charles Kovac
Donna Kring
Mark Lekarczyk
Rusty Merrill
Suzanne Metzler
Marty Miller
Art Moore
Dave Moross
Ronald Morris
Bill Noe
Jon Nordby
Melissa Nowlin
Ronald Null

Patricia Plank
Julie Rush
Larry Rush
Jean Saunders
Mary Sauvain
Beverly Schulz
George Scott
Daniel Skousen
Lauren Sloan
Cindy Stempson
John Sullivan
Celine Terrell
Sherry Whitaker

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: KETO AIR FRYER MEATBALLS

Our low carb/good fat ketogenic study that was completed in 2021 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:

1 lb ground beef (75-25 blend)	1 tsp Creole seasoning
2 eggs	¼ C parmesan, grated
1 ½ tsp garlic powder	3 Tbl chopped fresh basil
1 tsp onion powder	Pepper to taste
1 tsp smoked paprika	Non-stick cooking spray

Directions:

- Combine beef, eggs, spices, parmesan and ½ the basil and mix well in medium bowl
- Roll meat into golf ball-sized shaped meatballs and set aside
- Preheat air fryer basket. Spray with cooking spray and cook for 8 minutes at 400°
- Serve hot with marinara sauce, parmesan and remaining chopped basil

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

***NEW Neuropong – Starts June 4th**

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

For more information contact Travis Lerma at (719) 495-5130 or tlerma@ppymca.org. Neurologicarehab.com / Fax: (719) 691-7994

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@neurologicarehab.com

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

My Husband's Guide to Living with Parkinson's: Humor and Support

By Jamie Askari – Parkinson's News Today, 3/19/24

EYEBROWS MAY RAISE WHEN MY HUSBAND SAYS HE'S "LIVING THE DREAM"

Whenever anyone asks my husband, Arman, how he is doing, his standard reply has become, "Living the dream." He usually gets a good laugh from this response, and they quickly move on to other topics. This has become his tagline, which seems to work well for him.

Living with a neurodegenerative disease with no known cure is probably not anyone's dream. But Arman always looks for the humor in life, and it's easy for him to find it. He doesn't complain, sulk, or ever feel sorry for himself. I genuinely believe he thinks he is "living the dream."

Since Arman's diagnosis of early-onset Parkinson's disease in 2009, he has remained steadfast in his pursuit of enjoying his life despite the difficulties of Parkinson's disease. Although he was only 38 at the time and had to step away from his lucrative career as a cardiologist, he was able to find the positive side of his situation. Instead of focusing on all that he had lost, he turned his attention to what he was gaining.

FINDING HUMOR IN GROWING OLDER WITH YOUNG-ONSET PARKINSON'S

You heard that correctly: He focused on what he had gained. What could someone possibly gain from a diagnosis of early-onset Parkinson's disease besides pain, suffering, loss, and complete devastation? Beyond the obvious negative things that come with any diagnosis, you might also be able to find a few positives intertwined. For Arman, while he lost the career that he had prepared his entire life for, he gained time at home with his wife and children. This time that he was gifted enabled him to be 100% present as his kids were growing up, something he would've missed otherwise. He also enjoys the perks of preferred parking on days when walking is difficult.

I "interviewed" Arman to share his wisdom and the tools he uses in order to help others who may be struggling. Here is what I learned from him, which continues to inspire me every day:

ARMAN'S GUIDE TO LIVING THE DREAM

- A strong support system is the most important part of my life. This is absolutely at the top of my list.
- Keep your friends and family close; maintain and nurture those relationships.
- Your cards have been dealt, so play them your way.
- It really doesn't matter what anyone thinks, so try not to worry about that.
- Things can always be worse.
- Look at time as a gift that has been offered to you.
- Happiness, enthusiasm, and positivity are contagious, so spread them around often.
- Laugh at yourself as much as possible, because laughter is free medicine with no copay or side effects.
- Although having a chronic illness is difficult, it doesn't have to ruin your life. You can still have a wonderful and fulfilling life; it just might look different from what you envisioned.

Choosing to live the dream and find the good in times of stress can make all the difference. Seek out the positive side of any situation. If you look hard enough, you just might find it.

Parkinson's may change the way emotions manifest in body: Study

By Molly Campbell – Technology Networks – Biopharma, 4/5/24

SENSATIONS SHIFT TO DIFFERENT AREAS IN PARKINSON'S PATIENTS

Parkinson's disease may change the way basic emotions — such as anger, disgust, fear, happiness, sadness, and surprise — are felt in the body, a study suggests, opening up new perspectives into the disease's nonmotor symptoms and how they're managed.

"The results of our study raise many interesting questions about the role of emotions in the symptoms of Parkinson's disease," principal investigator Juho Joutsa, MD, PhD, professor of neurology at the University of Turku in Finland, said in a university press release.

The study, "Bodily Maps of Symptoms and Emotions in Parkinson's Disease," was published as a brief report in *Movement Disorders*.

While Parkinson's is best known for its motor symptoms, it also brings about a range of nonmotor symptoms, from mood changes and sleep problems to cognitive decline, including trouble remembering and thinking, which can impact emotional well-being.

Emotions produce physical responses — such as a racing heartbeat or surging blood pressure — that shape the way people act. It's been suggested that people with Parkinson's may have trouble understanding social cues and how emotions make them feel.

HOW IDENTITY CAN EVOLVE AFTER A PARKINSON'S DIAGNOSIS

MAPPING EMOTIONS ON THE BODY

Joutsa's team, from the University of Turku and Turku University Hospital, studied whether emotions produce the same physical responses in people with Parkinson's as they do in healthy individuals by creating body images of emotional reactions, which they called bodily emotion maps.

The study looked at 380 people with Parkinson's and 79 healthy individuals who served as controls. The mean age for both groups was 67. While the Parkinson's group had more men and lower education levels, this didn't influence the results, the researchers noted.

First, patients were asked to describe the body areas where they were experiencing motor and sensory symptoms (clumsiness, stiffness, tremor, numbness, and pain) and bodily sensations associated with basic emotions (anger, disgust, fear, happiness, sadness, surprise, and neutral) by coloring in an outline of a human figure shown on a computer screen.

Clumsiness mapped primarily to the distal limbs, stiffness to the trunk and limbs, and tremor to the hands. "The bodily maps of ... motor symptoms matched well with clinical localization of

these symptoms," the team wrote.

Unlike motor symptoms, which were experienced in different areas of the body by Parkinson's patients than by controls, numbness and pain mapped to the same areas in both groups. However, bodily patterns were more widespread in Parkinson's than in controls.

To study how patients experience emotions compared with controls, the researchers asked the participants to think carefully about their responses to anger, disgust, fear, happiness, sadness, surprise, or a neutral emotion, and then separately color in the areas of the body where they would feel a loss or an increase of sensation. The body outline mapping emotions didn't separate the front side from the back, "because emotions are typically localized inside the body rather than superficially," the researchers wrote.

ANXIETY IS COMMON IN PARKINSON'S, LINKED TO WORSE LIFE QUALITY: STUDY

ANGER SENSATION REDUCED, SHIFTED IN PARKINSON'S PATIENTS

Compared with controls, patients described no or less intense emotional responses, possibly because of a dysfunction of the autonomic nervous system — the network of nerves that control automatic bodily functions such as heart rate and blood pressure — often seen in Parkinson's.

This difference was most pronounced in the sensation of anger, which for controls was focused in the chest area, while in Parkinson's patients it was reduced and shifted to the abdominal region as the disease progressed.

The team noted that none of the emotion-related sensations was "associated with levodopa equivalent daily dose," a measurement that standardizes the effectiveness of various Parkinson's medications.

In addition to anger, patients localized the sensations of disgust, fear, and surprise to different areas compared with controls. Bodily patterns of happiness and sadness were less widespread in patients than in controls, suggesting Parkinson's changes how emotions are felt in the body.

"The non-motor symptoms of Parkinson's disease have a significant impact on the patients' quality of life," said researcher Kalle Niemi, MD, who led the study. "The results of our study highlight yet another non-motor phenomenon."

While the clinical relevance of the results has yet to be determined, the team suggests bodily emotion mapping could be used to study other neurological diseases. "Extending our research method to other diseases offers new possibilities for neurology research," Joutsa said.

Stool Transplant Improves Motor Function in Parkinson's Disease Patients

By Margarida Maia, PhD – Parkinson's News Today, 5/1/24

A small trial found that fecal microbiota transplantation improved motor symptoms in Parkinson's patients.

A Phase 2 clinical study named GUT-PARFECT found that fecal microbiota transplantation (FMT) improved motor symptoms in Parkinson's disease patients.

"Our results are really encouraging!" Dr. Arnout Bruggeman, a researcher at the VIB-UGENT Center for Medical Biotechnology at the University of Ghent, and first author of the study, said. "After 12 months, participants who received the healthy donor stool transplant showed a significant improvement in their motor score, the most important measure for Parkinson's symptoms."

The research, published in *eClinical Medicine*, was led by neurologist Professor Patrick Santens from the University Hospital Ghent and Professor Roosmarijn Vandenbroucke, group leader at VIB.

A NEW APPROACH TO TREATING NEURODEGENERATION

FMT—also known as a stool transplant— involves collecting feces from a healthy donor and inserting it into a patient's gastrointestinal tract (GI).

The logic behind the clinical use of FMT is that a disease underpinned by microbial dysbiosis in the gut could be improved or treated by introducing healthy bacteria and restoring the gut microbiome. While the procedure might sound grim, it has demonstrated effectiveness for a range of conditions. In clinical practice, it is mainly adopted for the treatment of persistent infections with *Clostridium difficile*.

Despite decades of research and countless clinical trials, neuro-degenerative diseases such as Alzheimer's and Parkinson's lack efficacious treatments. Recently, the research community's attention has turned towards novel or alternative factors, which may affect the onset or management of these conditions, such as the gut-brain axis.

Parkinson's disease is characterized by the formation of alpha-synuclein protein clumps, which damage nerve cells producing the neurotransmitter dopamine in the central nervous system. A lack of dopamine causes the hallmark symptoms of Parkinson's, such as loss of muscle control, tremors and stiffness.

A growing body of research demonstrates GI dysfunction is prevalent in Parkinson's patients prior to symptom development. Alpha-synuclein protein clumps have also been observed in the GI system during the early stages of Parkinson's, which, in animal models, appear to reach the brain via the vagus

nerve. These emerging links between Parkinson's and the gut microbiome inspired the neurology department at UZ Gent; they wanted to explore whether FMT could significantly impact the evolution of Parkinson's disease over the course of one year.

PARKINSON'S DISEASE PATIENTS' MOTOR SCORES IMPROVED 12 MONTHS AFTER FMT

The GUT-PARFECT trial was a double-blind, placebo-controlled and randomized Phase 2 clinical study. A total of 46 Parkinson's disease patients, aged 50–65 years, were recruited and randomly assigned to receive nasojejunal FMT from a healthy donor (22 participants) or their own stool (24) as a placebo. Santens and colleagues analyzed changes in the Movement Disorders Society-Unified Parkinson's Disease Rating Scale (MDS-UPDRS) motor score as the primary outcome. Scores were collected at baseline, and at 3-, 6- and 12-months post-FMT.

"The change in MDS-UPDRS motor score from baseline to 12 months post-FMT was significantly different between treatment groups," the authors described. The improvement was most pronounced between the 6-to-12 months interval, which suggests that FMT could have long-lasting effects in Parkinson's disease patients. FMT from healthy donors also reported a reduction in constipation, an inconvenient symptom for many Parkinson's patients.

An important and unresolved issue in this study, as professed by the research team, is that the placebo group also demonstrated a large and relatively long-lasting response to autologous FMT. The MDS-UPDRS motor scores were significantly different between the treatment and placebo groups only at the 12-month follow-up mark, and not before.

"While we can only speculate, it's plausible to hypothesize that the clinical differences observed might be aligned with the effects on gut motility, as evidenced by the radiopaque pellet test results at the six-month evaluation. Another critical aspect to consider is the recent findings indicating significant alterations in the gut microbiome following autologous FMT," the authors said.

"Our study provides promising hints that FMT can be a valuable new treatment for Parkinson's disease," Vandenbroucke said. "More research is needed, but it offers a potentially safe, effective and cost-effective way to improve symptoms and quality of life for millions of people with Parkinson's disease worldwide."

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 in our LENDING LOCKER that are free for the taking:

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

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: 2 sets of sheets 1 mattress pad	
Hospital gown	1
Hospital slippers – XL & XXL	2
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
Thick-it	1
Transfer pads – can handle a person up to 300 lbs	4
Attend advanced briefs, maximum protection–large –24 count	3 pkgs
Cardinal health guards for men - extra heavy absorbency -14 count	2 pkgs
Depend men's guards – 52 count – 1 unopened and 3 opened with a few missing	8 pkgs
Fitright guards for men – 52 count	1
Generic briefs, L/XL – 18 count	4 pkgs
Prevail daily male guards – one size fits all – maximum absorbency-14 count	2 pkgs
Prevail Nu-fit daily briefs w/ fastener tabs – 32"-44" size – maximum absorbency-16 count	2 pkgs
Women's Always Discreet s/m/ p/m maximum protection underwear – 42 count	2 pkgs
Women's Always Anti-Bunch extra long panty liners. Extra protection – 92 count	1 pkg

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PARKINSON'S PERSPECTIVE

JUNE 2024

Coming Events

See inside for more information

June 1st - Reg Mtg at Central United Methodist Church – 10 am; **Program:** Break-Out Sessions
Caregivers & Parkinsonians separate into different rooms to talk

July 6th - Reg Mtg at Central United Methodist Church – 10 am; **Program:** TBD

August 3rd - Annual Picnic at the Barn pavilion at John Venezia Park!!!

September 7th - Reg Mtg at Central United Methodist Church – 10 am
Program: Scam Prevention; **Speaker:** Scott Mathis, CSPD

October 6th - 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

More useful websites:

<https://parkinsonsnewstoday.com>; www.parkinsonrockies.org; www.parkinson.org; www.nwpf.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>