



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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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).

NOTE: We will be meeting again at Academy Christian Church for our November meeting since we haven't received word whether 1st Presbyterian Church will be open to us in the foreseeable future.

Next Meeting: Saturday, November 14th | 10 am-12:30 pm

Location: 1635 Old Ranch Rd, on the corner of Old Ranch & Hwy 83 (Voyager Parkway)

9:45 am – Come in a few minutes early to check in, greet other members and ask question.

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

— November Program —

Program: LSVT Big – Availability Of and Accessibility To Rehabilitation Services

Speakers: Joe Powell & Molly Jones of UHealth along with two PT students, Samantha Hawke and Catherine Granatir, currently doing clinical rotations with UHealth

About the Speakers: Joe Powell, PT, DPT, NCS: I graduated in 2011 from Wayne State University in Detroit, MI with my Doctorate in Physical therapy. I stated my career in Chicago, IL working at the Rehabilitation Institute of Chicago where I began specializing in treatment for neurological populations. This is where I became a certified LSVT BIG clinician (since 2012) and even helped to organize and run a Parkinson's specific screening clinic. I eventually moved to Colorado in 2014 to work for UHealth and received my Board Specialty Certification as a Neurologic Clinical Specialist in 2017 through the American Board of Physical Therapy Specialties (ABPTS).

Molly Jones, PT, DPT, NCS: I graduated in 2008 from Northwestern University in Chicago, IL with my Doctorate in Physical Therapy. I have been with Memorial Hospital/UHealth since January 2009, and currently treat a wide range of neurologic and vestibular diagnoses in outpatient rehabilitation at our Printers Park location. I received my Board Specialty Certification as a Neurologic Clinical Specialist in 2014 through the American Board of Physical Therapy Specialties (ABPTS), and am a certified LSVT BIG clinician for evidence-based treatment of patients with Parkinson's Disease.

Samantha Hawke, SPT: I am a physical therapy student from Northwestern University in Chicago, IL and will graduate in April 2021. I am currently on a clinical rotation in Colorado Springs with UHealth. I am loving my time in Outpatient neuro as this is the patient population I am interested in working with after graduation. I just recently took the LSVT GLOBAL course and got certified to administer the LSVT BIG protocol while on this clinical and am very excited to put it to use in the clinical setting to help patients with Parkinson's Disease improve their function and quality of life.

Catherine Granatir, SPT: I am a physical therapy student from Northwestern University in Chicago, completing my second of four clinical rotations in outpatient neuro physical therapy with UC Health. I will be graduating in April 2021, and hope to have the opportunity to work with the neurological population, as I have really enjoyed my experiences with this population thus far. I have recently become LSVT BIG certified and hope to implement this treatment approach into my future career when working with patients with Parkinson's Disease in the future.

The program will be followed by a potluck lunch.

The November Potluck Main Dish: Turkey Main Dish, Turkey & Gravy, provided by CPF

If you would like to sign up to be a provider of a side dish or dessert to the November meeting you can sign up through our website or you can contact Stephen Rudawsky at [redacted] or potluck@co-parkinson.org, no later than Wed. November 11th and tell him what you would like to bring. If you'd like to go through the website, go to the "Events" page of the website and find the meeting you're volunteering for and select "Event Details". That will take you to the main sign-up page. In addition to the meeting information, you will see how many chefs and the number of servings per batch are needed. Click on "Sign Up" in the box and then select "Submit and Sign Up" which will take you to a page where you will select how many of the number of chefs you are signing up for. For example, if the # of servings requested is 10 but you're making 20 servings then the quantity you would select should be 2...the equivalent of 2 chefs. There is also a place for any comments you may have there. You must then provide your name & email address. When finished, select "Sign Up Now" and you will receive a confirmation email and your information will be sent to our potluck coordinator, Stephen. This capability should help make Stephen's job considerably easier. To return to the website, close the sign-up tab at the top of the screen.

Remember that bringing food for the potluck is voluntary.
We look forward to seeing you there!

The President's Corner

| Jill Reid - Interim President, CPF & CSPSG



Because I earned a degree in Living with Parkinson's Disease from the School of Hard Knocks in spite of not having PD myself, I have learned a lot about how PWP's (people with Parkinson's) can minimize the potentially devastating effects of the later stages of Parkinson's. By deciding to be intentional in how you deal with Parkinson's, you can slow down the progression of the disorder and even reverse the symptoms you're currently experiencing.

Being intentional can be hard work. So why, you ask, would anyone want to go to the trouble and effort of being intentional in his or her dealings with a progressive disorder? I mean, isn't it going to progress no matter what he or she does? The answer is yes, it's going to progress no matter what. **BUT PD doesn't have to progress to its classic later stages, and having PD doesn't have to be the only focus of your life.**

How, you ask, does a PWP become intentional in dealing with PD? By deciding to do whatever it takes to slow the progression and doing those things consistently and despite apathy and fatigue, cultivating a positive attitude, beating back apathy no matter what, doing everything you can possibly do for yourself instead of letting others do for you, setting goals for yourself, continuing to do the things you've always enjoyed doing, being with friends, and taking up new hobbies, to name a few (for more ideas, see Greg Ritscher's book, [Rising Above Parkinson's](#), available at our monthly meetings for \$10 or online).

So what are some of the benefits of being intentional in how you live with your Parkinson's? Let's list the obvious ones: 1) It can make living with PD much easier; 2) It can slow the progression of the disorder; 3) It can keep PD and your disabilities from ruling your every moment; 4) It can enable you to focus on others and to help them; 5) It can prolong your abilities; 6) It can prevent isolation, which can have a more devastating effect on your life than having PD; and 7) It can ease the caregiving burden on those who love you.

I'd like to focus on number 7. If you have the good fortune to have a loving person in your life, one who has taken on caregiving responsibilities because he or she loves you and is committed to your well-being, you owe that person and yourself your very best efforts to making caregiving for you not be a burden but a joy. That way, your loved one will not burn out from the weight of caregiving and cease being able to care for you. I don't know about you, but I'd want that person in my life for the long term!! After all, you love him or her or them as much, if not more, than he or she loves or they love you, right?

So with all the above in mind, we are bringing in Joe Powell and Molly Jones for the November presentation. Both PTs at UC Health, they will speak about major therapies that could be part of your intentional program to live your best life with Parkinson's, things that will slow the progression of PD, will help you live well with PD, and will make it easier for your loved ones to care for and help you.

Upcoming Parkinson's Events:

The Focused Ultrasound Foundation (FUS) is holding its next biennial conference virtually because of COVID-19 concerns. CSPSG member, Ron Nickelson, was one of the first volunteers to undergo this procedure some years ago in hopes of diminishing his Parkinson's symptoms and is very pleased with the outcome.

The date is November 8-13.

For information and to sign up, go to www.symposium.fusfoundation.org.

To learn more about Ron's experience go to www.fusfoundation.org/news/focused-ultrasound-was-worth-the-wait-for-parkinson-s-patient.

Due to limited space in this month's newsletter, please see past newsletters for information normally included; i.e., other local Support Groups, PD Exercise Classes, and other opportunities.

SAD NEWS: Barbara Devoll passed away October 12th, 2020. Our heartfelt condolences to her family and friends.

HAPPY
november
BIRTHDAY!

Steven Boswell
Eric Brewner
Ron Brown
Fred Carrico
Jerry (Smokey)
Chism

Susan Coddington
Dorothy Filippi
Dick Geist
Doug Gibb
Richard (John)
Hero

Brenda Hicks
Harry (Bill) Killa
Joan Lydon
Donna MacDonald
Carolyn Mangold
Pat Murphy

Janet Nielson
John Perrin
Neal Purdy
John Reid
Jack Risley
John Rogers

Joanne Snelling
Karen Wilson
Diane Winkler
Marilyn Wisler

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

**Thank
You!**

Thanks to **ALL** who brought food and to those that helped setup and cleanup at the October meeting!

October Executive Meeting

November 17, 2020 at 12:00 at a place to be determined.

You will be notified by email. Contact Linda at secretary@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 Linda can contact you if anything changes.

DECEMBER / JANUARY NEWSLETTER INPUT

DEADLINE:

NOVEMBER 23RD

Call or e-mail Julie at:

db_mgr@co-parkinson.org

Coronavirus and Parkinson's Disease

For information
on Corona Virus and
Parkinson's Disease
go to:
[www.parkinson.org/
CoronaVirus.](http://www.parkinson.org/CoronaVirus)

October 10, 2020 Program Review

| by Linda Christian, Secretary

Parkinson's Disease Update 2020,

Presented by: Dr. Brian Grabert, MD

Dr. Grabert began his presentation by welcoming both Zoom and in person attendees to the meeting. He asked all of us how we were doing with COVID-19 and there were many sighs. Dr. Grabert then said he wanted to take time to thank all the front-line workers and introduced Melinda McClendon, NP a team member at UC Health Neurology Clinic who was in attendance for our meeting today. He also expressed his gratitude for the two month's assistance Major Melinda McClendon gave to New York City when they needed it the most.

Dr. Tidman is making her presentation slides available for the CPF website. The balance of this review is comprised of Dr. Tidman's slides with some additional information/comments provided during the presentation.

Dr. Grabert then stated that his presentation would cover the following:

- New Research Approaches
- Sinemet still the "gold standard"
- Newest Medications
- Symptom Burden as it affects Quality of Life
- Management of Hallucinations
- Management of Anxiety

The first slide displayed an example of Lewy bodies, which Dr. Grabert explained are abnormal protein deposits. He further explained Lewy bodies are made of a protein called alpha-synuclein. Dr. Grabert added that in 1912 Dr. Friederich Lewy, a German neurologist discovered these abnormal protein deposits in individuals with Parkinson's disease.



Dr. Grabert told us that there has been a paradigm shift in the approach to Parkinson's disease.

In his next slide, Dr. Grabert provided a glossary of terms:

- ON: when your Medication is working for motor symptoms [tremor, stiffness, bradykinesia]
- OFF: when your medication is not working for motor symptoms [defined operationally as 8-12 hours without medication]
- Axial Symptoms: Midline [less responsive to CD/LD] {speech, swallowing, gait which has 4 components: base/cadence/posture/presence or absence of freezing}
- Non-Motor Symptoms: most all others except 3 cardinal motor Sx's of PD

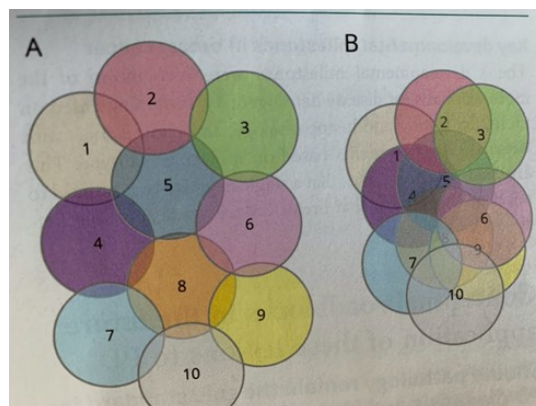
Dr. Grabert then moved to - New Research Approach: Quest for Disease Modifying Drugs /Cure

- Re-thinking Parkinson's Disease [since discovery of dopamine in 1962 as the deficiency neurotransmitter in PD, research has centered on metabolic pathway to find a "cure"]
- Been this Move away from a single disease model [dopamine metabolism at the center] with various rates of progression to a model of multiple genotypes/phenotypes

He then provided the following information regarding genotypes/phenotypes:

- A genotype is your profile based on single or multiple genetic "defects" [mutations] Changes in the nucleotide sequence of the genetic material (i.e. DNA, or RNA,) usually caused by copying errors during replication resulting in an abnormal protein
- A phenotype is how you are described in the clinic, based on symptoms and signs [exam findings]

The following slide depicts (A) New research approach utilizing multiple Geno/Pheno types vs (B) Single disease approach (helpful but disappointing)



Next, Dr. Grabert discussed PD GENERation: Genetic Testing:

- PD GENERation: Mapping the Future of Parkinson's Disease: Is a first-of-its-kind national initiative that offers genetic testing for clinically relevant Parkinson's-related genes [Available in PD Centers of Excellence]
- 17% tested positive for at least one mutation linked to PD

He added that he would like to encourage our support group members to enroll in PD GENERation genetic testing. As of July 2020, 291 participants had enrolled with a goal of 215,000 participants. Dr. Grabert explained that 23 & Me only tests for 2 genetic mutations where PD GENERation tests for 7.

Dr. Grabert moved to the next topic of Current Research to Find Disease Modifying Treatments:

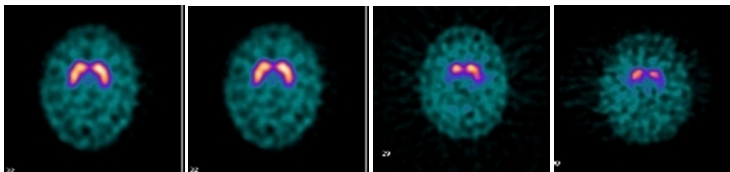
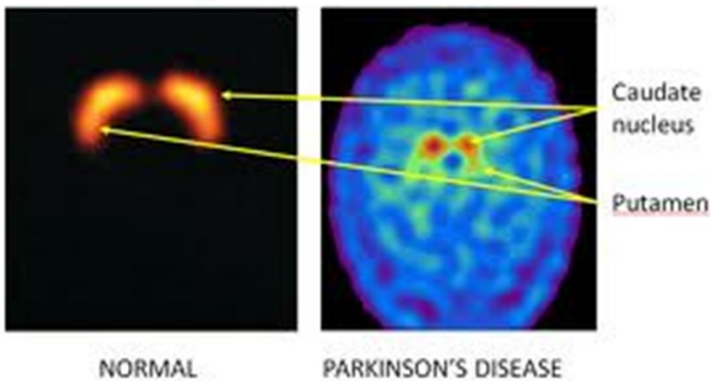
- The single disease approach that targets drugs in dopamine metabolism pathway [still important, but disappointing research over several decades]
- Efforts to target biomarkers of PD including studying genetic mutations causing or increasing the risk to develop PD [since mutations code for proteins they are a form of a biomarker]

He then provided us with a definition of biomarkers in Parkinson's disease and one example of a biomarker in research:

- Definition - a measurable substance in an organism whose presence is indicative of some phenomenon such as disease, infection, or environmental exposure.
- Example:
 - Dopamine transporters are depleted in PD [DAT scan 2012]
 - Isoflupane I -123 injected several hours before scan, is biomarker for Dopamine Transporters
 - Crosses BBB and labels or marks density of Dopamine Transporters
 - Nuclear medicine camera images DATs concentrated in the Putamen and Caudate

The following slides contained examples of research targeting

DaTScan which measures presynaptic dopamine transporters in the nerve terminals



biomarkers:

These scans depict

- a normal scan, one side is normal, the other not and one clearly abnormal

Is there No Parkinson's Disease ?

- Parkinson's Disease is Heterogeneous
- There is not just one Idiopathic PD
 - ? How many Genotypes?
 - ? How many Phenotypes ?

Dr. Grabert then begins his coverage of medications old and new -

- Symptomatic Medications: Sinemet is the gold standard
 - After 45 years CD/LD [Sinemet] is still leading the race 🏆 !!

Competitors to CD/LD: Medication Choices?

- How many?

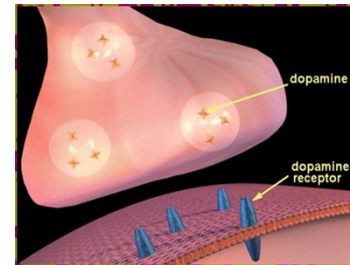
Medication Categories [5-6] for Parkinson's Motor Symptoms:

- Dopaminergic replacement : L-Dopa or CD/LD
- Receptor agonists [ropinirole & pramipexole & rotigotine patch]
- MAO-Type B inhibitors: inhibits the degrading pathway for

dopamine [selegiline, rasagiline & safinamide] [indirectly dopaminergic][approved for initial & add on Rx]

- COMT inhibitors: prolongs action of CD/LD [entacapone] [in-directly dopaminergic][only good with CD/LD]
- Amantadine: NMDA antagonist & releases dopamine from storage [risen to second place ?]
- Anticholinergics: trihexyphenidyl & benztropine [I haven't used in 20+ years]

Dopaminergic Drugs: Mechanism of action:



Brief Chronology of Dopaminergic drugs

- L-Dopa [without carbidopa] 1967 [Up to 16gms =160 tabs]
- Sinemet[Brand name CarbiDopa-LevoDopa] 1975
- Symmetrel [amantadine] 1976
- Eldepryl [Brand name selegiline] 1989
- Sinemet -Controlled Release 1991
- Requip [ropinerole] & Mirapex [pramipexole]1997
- Comtan [Entacapone] 1999
- Stalevo [CD/LD/entacapone] 2003

Chronology of Dopaminergic & other PD drugs

- Northera [for orthostatic Hypotension] 2014
- Rytary [Extended Release CD/LD] 2015
- Duopa [intestinal gel L-Dopa] 2015
- Nuplazid [Pimvanserin] 2016
- Xadago [safinamide] [MAO-B inhibitor] 2017
- Gocovri [extended release Amantadine] 2017
- Inbrija [inhaled L-Dopa] 2018
- Nouriang [istradefylline][adenosine antagonist] 2019
- Ongentys [opicapone] 2020

Newest Medications - Last 4 Approved

- Gocovri [extended release Amantadine] 2017
- Inbrija [inhaled L-Dopa] 2018 limited use
- Nouriang [istradefylline][adenosine antagonist] 2019
- Ongentys [opicapone] 2020

Sinemet [CD/LD]: the gold standard

- There is no PD medication more potent nor more appropriate for initial treatment of PD than immediate release CD/LD [or Rytary if affordable]
- A 14 year randomized trial of Agonists V. CD/LD found no major benefit of starting an agonist first [enthusiasm in 1997 was negated by 2008 publication]

Large Longitudinal Study 2008

- "14 year final report of the randomized UK trial comparing agonist vs. L-Dopa in PD" Neurology® 2008;71:474-480
- Conclusion: Initial treatment with the dopamine agonist bromocriptine did not reduce mortality or motor disability and

the initially reduced frequency in motor complications was not sustained. We found no evidence of a long-term benefit or clinically relevant disease-modifying effect with initial dopamine agonist treatment.

Why chose one L-Dopa over another as initial treatment of Parkinson's?

- Sinemet immediate release [cheap;effective;predictable absorption]
- Stalevo: [theoretically better: longer DOA but ironically more dyskinesias]
- Sinemet CR [sustained or controlled release theoretically better but erratic absorption, at least an hour delayed onset . Best limited to nighttime Rx]
- Duopa and Inbrija ["niche" drugs for selective population]
- Rytary : [combination of immediate release 1/3 and two types of extended release L-Dopa. For many cost prohibitive]

Amantadine: Immediate Release

- Originally licensed to Rx Influenza A
- Discovered serendipitously to help PD April 1968, 58 yr. F. with PD reports improvement in PD Symptoms when Rx for flu
- Led to a study of 163 Pts [JAMA 5/19/69] - Amantadine: Parkinson's Disease

Robert S. Schwab, MD; Albert C. England Jr., MD; David C. Poskanzer, MD; et al

Robert R. Young, MD - JAMA. 1969;208(7):1168-1170.

▫ Abstract

Sixty-six percent of a group of 163 patients with Parkinson's disease exhibited subjective or objective improvement of their akinesia, rigidity, and tremor while receiving amantadine hydrochloride. Of those showing improvement, benefits were sustained in 58% for a period of three to eight months. The maximum daily dose was 200 mg.

Amantadine: two targets

- Worthy of first add on drug for :Targets motor Symptoms: tremor, rigidity, bradykinesia
- Definite treatment of dyskinesia: Try immediate release amantadine first , then Gocovri [if no or limited response]

Extended Release Amantadine

- GOCOVRI
- once a day dosing at bedtime two capsules [137 mg size]
- Approved 2017
- achieves twice the blood levels of immediate release amantadine
- Most common side effects: falls hallucinations, edema, constipation
- Try immediate release then GOCOVRI

Opicapone [ONGENTYS]

- Approved April 2020
- Long acting COMT inhibitor
- Better than entacapone [COMTan] by 45 minutes longer L-Dopa effect
- used for End of Dose or Wearing off
- Cost and coverage to be determined

- not used yet at UC Health

Next, Dr. Grabert covers - Symptom burden as it affects Quality of Life, first providing a definition for Quality of Life (QoL)

Quality of Life : Definition

- NOUN
 - the standard of health, comfort, and happiness experienced by an individual or group

Quality of Life [QoL]

- Survey of 612 Patients H/Y Stages 2-5 & 5 years since Dx. [21 symptoms]
- QoL ranked on 1-10 scale [1-4 = poor]
- 21 symptoms ranked as Odds Ratio for poor QoL
- Top 5 were
 - Depression
 - Confusion
 - Hallucinations
 - Memory loss
 - Anxiety

QoL continued. Motor Sx's Intermediate Impact

- The motor symptoms ranked:
 - Dyskinesia 9th
 - Tremor 11th
 - Slowness 13th
 - Stiffness 16th

QoL : Hallucinations

- Along with Delusions constitutes PD Psychosis
- Up to 50% will eventually develop hallucinations [usually visual]

Major Symptoms defining PD Psychosis

- **Delusions** are false, fixed beliefs, that are held despite evidence to the contrary
- Well **structured Visual Hallucinations**
- Hallucinations **in other sensory modalities** sensory perceptions: auditory gustatory, olfactory, tactile

Treatment of Hallucinations [UFlorida]

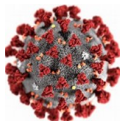
- Check for: UTI, pneumonia, other infections
- Eliminate or reduce PD medications:
 - anticholinergic drugs
 - amantadine
 - selegiline or rasagiline
 - dopamine agonists
 - (COMT) inhibitors
 - finally levodopa
- Assess for dementia or cognitive impairment

Hallucinations persist:

- Treat dementia if present:
- Add antipsychotic drug :
 - quetiapine: 4 randomized controlled trials, totaling 153 patients with PDP, failed to show efficacy vs placebo.
 - **Clozapine** consistently demonstrates efficacy in randomized controlled trials in the treatment of PDP
 - Pimavanserin is a selective and potent serotonin

5-HT_{2A} inverse agonist without dopaminergic, adrenergic, histaminergic, or muscarinic affinity.¹³ This novel atypical antipsychotic approved on April 29, 2016, and is the only FDA approved Rx for the treatment of hallucinations and delusions associated with PDP

QoL : Anxiety



makes it worse, doesn't it?

Anxiety may pre-date PD by > 20 years

- Mayo Clinic Cohort Study of Personality and Aging
- Minn. Multi-phasic Personality Inventory {MMPI}
 - Dr. Grabert noted that this is a long questionnaire taking 1 – 2 hours to complete
- High scores on the anxiety scale were associated with PD dx > 20 years later

Anxiety and PD

- increased prevalence due to disease process [40%] not reaction to the diagnosis
- no Class 1 studies of medications
- YOGA and cognitive behavioral therapy Clinical Trials Update July 23/30, 2019
- Yoga for Anxiety and Depression Associated With Parkinson Disease
- SSRI's best empirical choice Rx

Randomized Clinical Trial: JAMA Neuro 4/8/2019

- Effects of Mindfulness Yoga vs Stretching and Resistance Training
- Exercises on Anxiety and Depression for People With Parkinson Disease A Randomized Clinical Trial: Ninety minutes weekly for 8 weeks vs. 60 minutes Stretching and resistance training

Results: Among patients with mild-to-moderate PD, the mindfulness yoga program was found to be as effective as SRTE in improving motor dysfunction and mobility, with the additional benefits of a reduction in anxiety and depressive symptoms and an increase in spiritual well-being and HRQOL.

More Question's?? – Dr. Grabert ended his presentation by taking questions from both in person and Zoom attendees -

1. What about Seroquel? Is it still being used for hallucinations?

- Now Nuplazid (Pimavanserin) is being used for Parkinson's patients experiencing hallucinations.

2. A friend realizes that he has hallucinations with his Parkinson's, is this normal or do most people not realize they are having hallucinations?

- Yes, most patients realize they have them. It's important to treat if the hallucinations are frightening or threatening.

3. We know that 80% of patients with Parkinson's disease is because of environmental exposures, why does one person get Parkinson's and another does not with the same exposure?

- We call this the second hit hypothesis. Two individuals can have the same environmental exposure, one has a low vitamin D level and the other does not. The individual

with the low vitamin D level gets Parkinson's and the other does not. Individuals with low vitamin D levels have a higher risk of Parkinson's disease.

4. What about Vitamin D and COVID-19?

- There could be a protection, it can't hurt to take Vitamin D.

5. Mirapex as an add on therapy, how do you dose?

- .5 mg., 3 x's per day up to 1.5 mg, 3 x's per day. Excellent for nighttime. Daytime function is what doctor's assess.

6. Do people get tired taking Mirapex?

- Yes, sleepiness can occur. Some that take Sinemet also experience sleepiness. With Mirapex, you can fall asleep quickly at any given time, causing a hazard.

7. Will you address fatigue?

- Fatigue is common in Parkinson's disease
- Lower your medication dosage if possible
- Caffeine may help, there may be a neuro protective component
- Modafinil can be used, expensive, \$700 for 30 tablets. Good Rx can reduce the cost significantly. One support group member only paid \$20.95 vs \$700.

8. Does Modafinil help ADHD?

- Yes, it does help.

9. Does Azilect slow down the progression of Parkinson's disease?

- Same as Eldepryl, it may slow down the progression.

10. How do we know that Azilect does not slow down the progression of Parkinson's disease?

- It's proven to help symptoms, no study has proven that it slows down the progression of Parkinson's disease.

11. Can you provide more information regarding PD GENERation?

- You can enroll now through their website. This can be very helpful in assessing genetic risk for Parkinson's.

12. How safe is the data being used compared to 23 & Me?

- Sponsored by the Parkinson's Disease Centers for Excellence. Not a commercial DNA organization that agrees to share data.

13. What are the long term effects of Amantadine on cognition?

- Not aware of that data. Dr. Grabert will research. He feels cognitive decline is more the natural progression of Parkinson's disease rather than the medication.

14. Can Amantadine cause dry mouth?

- Yes, it's a NMDA antagonist with anticholinergic properties.

15. Are there any breakthrough medications for falls?

- Not that I'm aware of. Most falls are due to the disease progression and freezing.
- If your freezing is related to medication off times, you may be a good candidate for DBS
- A Japanese study ended early because it didn't work
- Physical therapy helps
- Individuals do better with good coaches
- LSVT – Big helps

16. Do individuals with Parkinson's disease have an increased sensitivity to heat/cold?

- The disease probably makes you more sensitive.

17. Can you discuss sleeping issues with Parkinson's disease?

- There's an algorithm for Parkinson's
- Adjustments to medication
- Melatonin can help in initiating sleep
- Mirapex might help
- This topic would be worth an entire presentation

18. Someone told me that tremors woke them up at night, is this possible?

- Tremors go away with sleep. When you wake up, tremors start, it may have been something else that awakened them.

Prescription Drug Savings!!

At the October meeting one of our members let us know about the GoodRX drug discount card that can offer a substantial savings in drug costs. It might be worth looking into. Click on the link

<https://www.goodrx.com/discount-card>.



Left: Dr. Grabert Zooming at the last meeting. Below: Meeting room at the Academy Christian Church location. Everyone's health and safety are our top concerns at our monthly meeting. Social distancing and mask wearing for those who are concerned about COVID.



Genetic Testing for Parkinson's Disease

Sponsored by Parkinson Foundation, formerly National Parkinson Disease Foundation

PD Generation: Mapping the Future of Parkinson's Disease is a national initiative that offers genetic testing for clinically relevant Parkinson's-related genes and genetic counseling at no cost for people with Parkinson's disease. Participation can be either in-person at one of their participating Centers of Excellence sites or from home through a telemedicine appointment and at-home cheek swab collection kit.

For information click on the link <https://www.parkinson.org/PDGENERation> or for questions about enrollment, email genetics@parkinson.org

Beneficial Information for People with Parkinson's

| by Karl Stengel

This month I will give you links to three YouTube videos. In the first video, a couple of physical therapists (Bob Schrupp and Brad Heineck) tell you about fifteen common exercises many of us probably learned in school, or in boot camp, that they believe we should NOT do. They follow this with a second video, showing some exercises to do instead.

The first video - exercises you should NOT do (12.5 minutes long) - The exercises are:

1. Toe touches (puts too much stress on back, especially discs);
2. Neck stretches;
3. Standard sit-ups (excessive stress on back);
4. Dips (shoulder impingement);
5. Running on a slanted road in one direction only;
6. Military press (shoulder impingement);
7. Upright rows to chin (lower back);
8. Bent over rows (esp w straight legs) (lower back);
9. Squats below 90 deg w weights (knees and lower back);
10. Leg extension (knees);

11. Windmills (touch right foot w left arm etc.) (lower back);
12. Side dips w weight (lower back);
13. Push-ups w palms far apart (shoulder);

Bob & Brad show alternative exercises that you CAN do (17 min)
<https://www.youtube.com/watch?v=e8dyPfxk42M>

The third video gives some info on running:
 Running info from Bob & Brad (16 min)
https://www.youtube.com/watch?v=zZmIYaM_1ZY

Colorado Parkinson Foundation, Inc.

1155 Kelly Johnson Blvd.

Suite # 111

Colorado Springs, CO 80920

Parkinson's Perspective

NOVEMBER 2020

Coming Events

See Inside for Details, Phone Numbers, and for More Information

November 14th - Reg Mtg and Thanksgiving Potluck Lunch at the Academy Christian Church - 10 am

Program: LSVT Big – Availability Of and Accessibility To Rehabilitation Services – **Speaker:** Joe Powell & Molly Jones, UCHealth

December 12th - Reg Mtg at Academy Christian Church – 10 am, **Program:** Christmas Party!!! Entertainment provided by Ginger Clark

January 9th - Reg Mtg at the Academy Christian Church – 10 am, **Program:** Parkinson's 101 – **Speaker:** Jill Reid

- ◆ CSPSG Caregivers meeting is the 3rd Friday of each month – Contact Charlene at [REDACTED]
- ◆ Tri-Lakes PD Support Group meets the 3rd Sat of each month – Contact Syble (719) 488-2669 or John at robun2good@gmail.com.
- ◆ NeuroRehab Project at ORA – Call Danielle for PWR!MOVES or Rachel for Speech Therapy & Swallowing at 719-265-6601.
- ◆ YMCA- Parkinson's Wellness Recovery Exercise – call (719) 329-7295 or email wellness@ppymca.org.
- ◆ Colorado Springs Senior Center: Exercise, Yoga, and TaiChi for older adults - (719) 955-3400 or <http://www.ppymca.org/colorado-springs-senior-center/about-us>.
- ◆ UCCS Center for Active Living – at the Lane Center - Power Moves group exercise classes. Also: Balance & Agility Class for information: Call 719-255-8004 or email CAL@uccs.edu.
- ◆ Max Capacity NeuroFitness – Contact Emily at (719) 213-3996 or visit maxcapacitypt.com
- ◆ The Resource Exchange – the single-entry point for Medicaid long-term care – must be eligible for Medicaid and for Social Security disability.

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