

Parkinson's Perspective

Newsletter of the Colorado Springs Parkinson's Support Group Colorado Parkinson Foundation, Inc.

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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 December and January meetings since we haven't received word whether 1st Presbyterian Church will be open to us in the future.

December Meeting: Saturday, December 19th | 10 am-12:30 pm

MEETING DATE CHANGE!! Our December meeting date has changed to the 3rd Saturday, December 19th, because of scheduling conflicts with church activities.

January Meeting: Saturday, January 9th | 11 am-1:30 pm <u>MEETING TIME CHANGE</u>!! Because of church activities conflicts, our January meeting time has changed to 11:00 am.

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

9:45 am, Dec. 19th and 10:45 pm, Jan. 9th – 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.

December Program: Annual Christmas Party!! Entertainment: Ginger Clark

Ginger will entertain us with her enthusiastic singing of old-fashioned Christmas music to get us in the holiday spirit. We are also going to have a White Elephant gift exchange if you'd like to participate (gifts of \$10 or less), an ugly Christmas attire contest (also if you'd like to participate) and games. Come join the fun!!!!!

January Program: Parkinson's 101

Speaker: Jill Reid, Educational Outreach

Jill will present the "annual" Parkinson's 101 program (annual in quotes because we didn't have a chance to present it in 2020 due to COVID-19). Designed for People with Parkinson's and their family-member caregivers, Parkinson's 101 provides invaluable information for those new to the disorder as well as for those who already have extensive experience with the disorder. It also includes practical advice on coping with Parkinson's on a day-to-day basis. Since the symptoms of each PWP's Parkinson's change to some degree over the course of a year, we present this briefing annually so that each of you can key in on the information that wasn't relevant to you in the past. Knowledge is power and enables us all the live well with Parkinson's, so plan to attend the January meeting at Academy Christian Church or join us on Zoom.

The December Potluck - Canceled! January Potluck - Casseroles (Beef, Chicken, Veggie, etc.) - *if not canceled.*

December - Because of new COVID-19 lockdowns, the church has asked us to cancel the potluck for the December meeting because we won't be allowed to take off our masks for any reason while we're in the church building. That means we won't be providing any beverages either. If you need to take pills or drink water, you will need to bring your own beverage and take it outside. So instead of lunch, we thought it would be fun for members to create individual single serving goodie bags to give to attendees to take home with them. The bags can contain cookies, candy, fudge, or any other Christmas goodies that would fit nicely into smallish bags.

If you would like to sign up to bring take-home goodie bags to the December meeting or to be a provider of the January main dish or a side dish, you can sign up through our website or you can contact Stephen Rudawsky at a or potluck@co-parkinson.org, no later than Wed. December 16th and/or January 6th 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!

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The President's Corner

| Jill Reid - Acting President, CPF & CSPSG



of Stephen and the unscheduled absence of Katherine Reed, who normally man the

kitchen for us, Carol Henrichsen, Julie Pfarrer, and Janet Adams stepped in and set up, served, and cleaned up. Bob Adams helped set up tables and chairs before the meeting, and Rich and Mary Sauvain sanitized the tables, put away tables and chairs, and helped talk was that the therapies, while targeting carry the kitchen supplies out to Julie's car; all movement and vocalization, also greatly imwithout anyone asking any of the three to do prove how the patients feel emotionally, and anything. They just saw the need and took we could "see and hear" that clearly in those care of it. Thank you so much for making that videos! Who knew??!! I encourage those of meeting run so smoothly!

Joe Powel and Molly Jones, PTs from UC Health (along with PT students Samantha Hawke and Catherine Granatir) did a great job In accordance with tradition, the December briefing us on the Lee Silverman Voice Treatment (LSVT) BIG and LSVT Loud. [The name LSVT refers to the original therapy, which was Ginger Clarke, a wonderfully talented woman Go to our website today at www.strictly for vocalization; LSVT BIG is the cur- with a golden voice! She loves singing the old parkinson.org to learn more and to sign up.

There are so many helpful rent therapy for PD movement issues while favorite Christmas songs as much as we love people in the world, and I LSVT Loud is the therapy for PD vocal issues]. hope I don't take the ones I If you didn't attend the meeting, either live or encounter for granted. Like at on Zoom, please read Linda Christian's great let Ginger do all the work. We'll also have a our November CSPSG meet- write-up in the following pages of this newsleting: in the scheduled absence ter. Unfortunately, our newsletter can't include turn to pick out a gift, you can either take an the amazing live videos that were part of the presentation. The videos showcased two real, live, honest-to-goodness Parkinson's patients before and after LSVT therapy (one took LSVT Loud and the other took LSVT BIG). The results of the therapies shown in the "after" videos were life-altering for those two people! One of the most interesting facts presented in the you with Parkinson's to take advantage of these therapies to get wonderful results that can last the rest of your life!

> meeting will be a holiday party. Instead of listening to a speaker, we will be entertained by 100% free to our members who have PD. Ginger Clarke, a wonderfully talented woman Go to our website today at www.co-

hearing them! Due to COVID, we won't include a sing-along, so we'll just sit back, enjoy, and White Elephant gift exchange-when it's your unopened one or steal one that's already been opened. If you'd like to participate in the gift exchange, bring a wrapped gift that costs less than \$10. It's a great chance to get rid of that awful wall hanging that Aunt Bertha gave you last year!

Don't forget to sign up for the important study that we will be starting in January on the effects of the ketogenic diet on the symptoms of PD. This diet has already been shown to "cure" other health conditions like Type 2 Diabetes, sleep apnea, and high blood pressure, just to name a few; and a similar study recently showed that the diet eases PD symptoms. But even if your PD symptoms don't improve, other aspects of your health most definitely will. Participating in our study is a WIN-WIN for everyone in it, no matter what, and it is

Important Warning! For anyone who has had Deep Brain Stimulation (DBS) or is considering having DBS!

Steven Galetta, MD, FAAN, Section Editor Neurology, Volume 95, Number 16, October 20, 2020 Editor's note: Beware of deep water after subthalamic deep brain stimulation

In the article "Beware of deep water after subthalamic deep brain stimulation," Drs. Waldvogel et al. reported 9 patients who lost their ability to swim after a surgery for deep brain stimulation of the subthalamic nucleus for Parkinson's disease (PD). The patients had all been proficient swimmers despite their PD but experienced deterioration of their swimming skills after deep brain stimulation (DBS). In response, Drs. Bouca-Machado et al. contend that such swimming difficulties are seen not only in patients with DBS but also in patients with long-standing PD, citing 2 previous studies - a survey in which most patients noticed a decline in swimming after disease onset with close to half having a drowning/near-drowning episode and a study of swimming styles that found that almost three-quarters of patients could not swim, with most having difficulties with movement, breathing, and positioning during the attempt. In another response, Dr. Sidiropoulos cites a previous case report by Drs. Bangash et al. of profound swimming difficulties in a patient who received DBS in the zona incerta noting that a similar risk may exist with other targets and that the difficulty may be a task-specific dystonia. Dr. Sidiropoulos inquires whether the authors considered DBS reprogramming strategies and requested details about the stimulation parameters. DBS brand, the axial Unified PD Rating Scale (UPDRS) sub-scores, and PD subtypes for these patients and wonders whether the robust reduction in levodopa dose post-DBS may have related to their worsened swimming abilities. Responding to these comments, the authors note that the patients reported in their study had in fact remained good swimmers despite their PD and only lost their swimming ability after DBS initiation. They report that inter-limb coordination - not dystonia - seemed to be the prominent problem in their patients. They clarify that the swimming difficulties could not be mitigated by reprogramming and do not name the DBS brand, deeming the procedure to be the key factor. They contend that if the swimming difficulties were related to the reduced dopaminergic medications, other motor tasks should also have deteriorated and that their patients showed improvement post-DBS including on axial UPDRS sub-scores. This exchange highlights the need for continued systematic study of swimming safety in patients with PD - both with and without DBS - and of the underlying pathophysiology of post-DBS swimming difficulties.

Parkinson's Disease is also Present in the Blood

An article in Medical Press By Aarhus University – October 2019

The behavior of immune cells in the blood is so different in patients with Parkinson's disease that it advocates for a new type of supplementary medicine, which can regulate the immune system and thus inhibit the deterioration of the brain.

These are the perspectives in a new study which researchers from the Department of Biomedicine at Aarhus University, Denmark, are behind. The article has just been published in the scientific journal Movement Disorders.

"The research project confirms a growing theory that Parkinson's disease is not only a brain disease, but is also connected with the immune system - both in the brain and the rest of the body." says Marina Romero-Ramos, associate professor of neuroscience, who leads the team behind the study.

PhD Sara Konstantin Nissen, who is the study's first author adds: "This knowledge may in the long term lead to the development of supplementary immuneregulating treatment being combined with the current medical treatment with the drug L-dopa, which only has an effect on the brain and the symptoms. We believe such an additional drug might help to slow down the progression of the disease," say PhD Sara Konstantin Nissen.

Parkinson's disease is characterized by the slow degeneration of the neurons in brain due to the abnormal accumulation of a protein call alpha-synuclein. This leads to the patients shaking and then to the slow, stiff movements which many people associate with the disease.

In the new study, researchers have subjected blood samples from 29 Parkinson's patients and 20 control Continued on next page 10...

November 14, 2020 Program Review

| by Linda Christian, Secretary

LSVT BIG® Physical and Occupational Therapy Empowering People with Parkinson's to Live BIGGER and BETTER

Presented by: Joe Powell, PT, DPT, NCS; Molly Jones, PT, DPT, NCS; Samantha Hawke, SPT; and Catherine Granatir, SPT

Joe Powell opened the presentation by welcoming in person and Zoom attendees. He also thanked Jill and The Parkinson's Foundation for having them here today to present on LSVT Big and LSVT Loud. Next, Joe asked, "who has heard of LSVT Big" and most individuals in the room raised their hands. He also asked how many had gone through the program and a few individuals raised their hands.

Joe then gave some background information on himself. He's been a physical therapist for approximately 10 years, he joined UC Health in 2014. Joe is a certified LSVT Big Clinician and received his Board Specialty Certification as a Neurological Clinical Specialist in 2017. Joe then introduced Molly Jones.

Molly provided background information on herself. She has been a physical therapist for 12 years and joined Memorial Hospital/UC Health in 2009. She currently treats a wide range of neurological and vestibular diagnoses in outpatient rehabilitation at the Printers Park location. She has been LSVT Big certified for 3 years. Molly then introduced Samantha Hawke.

Samantha told the attendees that she is currently a student at Northwestern University in Chicago and will graduate in April of 2021. She is on a clinical rotation with UC Health and just recently became LSVT Big certified. Samantha then introduced Catherine Granatir.

Catherine stated that she is also currently a student at Northwestern University in Chicago and will graduate in April of 2021. She is completing her second of four clinical rotations in outpatient neuro physical therapy with UC Health. She too recently became LSVT Big certified.

Joe began the group's presentation by presenting a slide with LSVT Global disclosures and research supporter information. His next slide explains - What you will learn!

- Key features of LSVT Loud and LSVT Big
- How these programs address motor and nonmotor symptoms of PD
- Overview of an LSVT Big session
- Research highlights on LSVT Big
- How exercise and therapy both help you
- How to get started with LSVT Big

He then noted that his team members Molly, Samantha, and Catherine would each be presenting sections of the presentation.

Joe continued by providing what LSVT stands for and gave us some background information regarding its development.

- LSVT stands for Lee Silverman Voice Treatment
- Dr. Lorraine Ramig began her lifelong research in 1987 to find an effective speech treatment for individual's with Parkinson's disease after meeting Mrs. Lee Silverman. It was after hearing her family's expressed wish to hear and understand her that began Dr. Ramig's quest. Dr. Ramig developed an effective speech treatment for individuals with PD, scientifically documented its effective-

ness, and implemented the treatment into real-world clinical practice. Later this protocol would be expanded to physical or occupational therapy program called LSVT Big.

The next slide provided the following data on Parkinson's disease worldwide and in Colorado:

Parkinson Disease (PD) - A Global Pandemic?

- Up to 8 million worldwide people are living with PD.
- 11,500 living in Colorado
- Number of people with PD is expected to DOUBLE by 2040

In addition to the data above, Joe provided more information regarding PD,

- Fastest growing neurological disorder
- 930,000 living in the US
- Approx. 60,000 new Americans are diagnosed with disorder every year
- \$52 billion per year in the United States alone is spent on treatment for PD

Joe explained the organization's mission - A Global Mission

To empower people with Parkinson's to restore and maintain their highest levels of functional communication, mobility, and independence in daily life through scientifically supported therapy programs, LSVT LOUD® and LSVT BIG®

Joe then provided the following:

When we ask patients newly diagnosed with PD about their goals of therapy one of the most common things we hear is "I don't want to lose anything." And for people who have had Parkinson's for some time, we find they simply want to do everything as they did it before Parkinson's disease. This could be improved movement, energy, balance, communication and more. Parkinson's impacts function in everything a person does at home, at work and in their recreational pursuits. The LSVT programs help you to restore and maintain your movement and voice which you need for normal function in everyday life beyond medication.

Next, Joe discussed - The LSVT Protocols: Based on 25 years of NIH funded research and clinical experience

- LSVT LOUD is a speech therapy Delivered by LSVT LOUD Certified Speech-Language Pathologists
- LSVT BIG is a physical/occupational therapy LSVT BIG is a physical/occupational therapy

Adding that LSVT recertification is required every 2 years. Joe also cautioned that not all therapists are able to administer this treatment.

At this point in the presentation a video example of LSVT Loud, before and after is shown to the attendees. The video is of a,

- 59-year-old female, 2.5 years since diagnosis
- Changes noted in her voice and speech

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- She is ON medications in the before and after videos and she has had no changes in medication
- Intensive one-month speech therapy program

Before therapy, her voice was not loud, she sounded hoarse, she said she would sometimes stutter, and her facial expression was minimal at best. When she was asked to say "AH" as long as she could, it lasted for only 7 seconds. The therapist asked her if she was talking less and she said yes, "nobody pays attention to me."

After the one-month speech therapy program, she was talking louder, did not sound hoarse, did not mention the stuttering problem and her face had much more expression. When asked to say "AH" highs and lows for as long as she could, it lasted 23 seconds. The female noted that her daughter and friends can now understand her, no one makes the comment "I can't understand you".

Another video is presented as an example of LSVT Big, before and after. This video involves,

- A 71-year-old male, 14 years since diagnosis
- Referred to PT for slowness, difficulty walking, falls and freezing
- Parkinson's medications were optimized before starting LSVT BIG
- No medication changes during the month of therapy
- Intensive one-month physical or occupational therapy program

In watching the side by side video, it was exciting to see the improvements that Bernie had made in just one-month of the therapy program. Before the treatment, Bernie was using a cane, would have episodes of freezing when approaching things like carpet, curbs, etc. His gait, balance and posture were clearly affected by PD. After the therapy program, Bernie was walking without a cane, walked with more speed, and improved posture. In the next slide, Joe presented some impressive before/after stats,

Bernie's Results:	<u>Before</u> <u>After</u>	
• Falls	1-2/month	0/month
 Assistive device 	Cane	None
Balance Confidence	37.5%	56.8%
 Gait Velocity 	0.35 m/s	1.17 m/s
 % of normal for age 	29.6 %	100%
Endurance	730 feet	1200 feet

- Bernie's Goals:
- ✓ To improve his walking
- $\checkmark~$ To go to the movies
- To play with his grandchildren
- $\checkmark\,$ To go out to dinner with friends and family

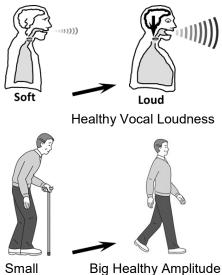
Next, Joe discussed the <u>Three KEY features of LSVT LOUD</u> and <u>LSVT BIG</u>, standardized, research-based, specific protocols

- TARGET: Bigness or Loudness (AMPLITUDE)
- MODE: Intensive and High Effort
- CALIBRATION: Solutions for Lasting Success

He then stressed that everything in the protocol has been standardized to assure success with each participant.

Joe provided examples of each - <u>TARGET – Amplitude (Loud</u> or Bigness)

Voice too soft/movements too small — Drive effort to increase amplitude



The next video was introduced showing Bob and the difficulty he encountered when trying to button his shirt. Before therapy, Bob struggled with buttons, after therapy, Bob was able to button his shirt in less time. Ques from his therapist helped him to form new habits enabling him to be more successful in this task.

MODE - Intensive and High Effort

- Intensity across sessions: Minimum dosage for efficacy!
- 4 consecutive days a week for 4 weeks in a row (16 SESSIONS)
- 60-minute sessions
- Individual therapy, (not group)
- Daily homework practice and daily carryover exercises (all 30 days of the month)

"Make a life-long habit of practice!"

Goal: Calibration

 LSVT BIG addresses the MISMATCH between one's perception of their movement and how others perceive it.

"I can't walk like this. People will think I'm crazy!"

Fox et al, 2002; Sapir et al, 2011

Joe added that if you look at movement as being between 0 - 10, 5 being normal and 10 depicting someone running, Parkinson's brings movement down to a 1 -2. Utilizing LSVT Big/Loud you would function at a 10 for the hour of therapy and at home. In the next slide, Joe stressed,

- Feedback is Specific, Personalized, Empowering and Meaningful Necessary for Calibration
- This remains the main reason why we have 1:1 session's

Samantha took over at this point in the presentation and then discussed,

5 KEY Principles that Promote Learning and Brain Change

- #1 Intensity Intensive practice is important for brain change
 - Drive Amplitude

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- Increase Repetitions
- Add Resistance and Balance Challenges
- Improve Accuracy



- #2 Complexity
 - Complex movements or environmental enrichment have been shown to promote greater brain change
- #3 Repetition
 - Brain change requires a lot of repetition!
 - "Practice until you can't get it wrong!"



- #4 Salience
 - Practicing rewarding and meaningful tasks activates circuits in the brain's Basal Ganglia.



- #5 Specificity
 - Train the deficits (small movements in PD)
 - Practice the actual functional task



Samantha then moved to - How? Address Key Non-Motor Symptoms

- · Changes in higher cognitive functions
 - Shifting focus from one thing to another
 - Slower thinking
 - Retrieving Information
 - Self-cueing
 - Sustaining attention
 - Divided attention
- Emotional Changes
 - Anxiety
 - Apathy
- Sensory changes
 - Pain, tingling, burning

- Generalized decreased kinesthetic awareness
- Self-perception/monitoring
- Autonomic changes
 - Hypotension, bowel/bladder, sexual, blurry vision, short of breath
- Sleep Disorders
- Depression
 - 25% major/17% minor
 - Precedes motor symptoms
 - May contribute to dementia
- Dementia
 - ♦ 30%
 - Occurs 6.6X as frequently than in elderly without PD

It was also note that motor and non-motor symptoms affect movement and motor learning in people with PD. LSVT BIG teaches you to self-cue, to recognize small movements and make them bigger and to focus on each exercise working toward these cognitive functions and making you aware of how much effort is needed for normal sized movement. Elicit emotional changes by putting you in control of your body.

Samantha and Catherine performed a visual example of an LSVT BIG Treatment Session

- Maximal <u>Daily Exercises Core Exercises "Building</u> <u>Blocks"</u>
 - ◆ Floor to Ceiling 8 reps
 - ♦ Side to Side 8 each side
 - Forward step 8 each side
 - ♦ Sideways step 8 each side
 - ◆ Backward step 8 each side
 - Forward Rock and Reach 10 each side (working up to 20)
 - Sideways Rock and Reach 10 each side (working up to 20)
 - Walking BIG
 - Distance/time may vary
- Functional <u>Component Tasks 5 EVERYDAY TASKS</u>
 <u>5 reps each</u>

For example:

- Sit-to-Stand
- Pulling keys out of pocket
- Using cell phone
- Hierarchy <u>Exercises</u>
 - Patient identified tasks: Getting out of bed, playing golf, Getting in and out of a car
 - Build complexity across 4 weeks of treatment towards long-term goal
- Homework
 - Includes all daily exercises, Functional Component Tasks and BIG walking assigned all 30 days
- Carryover <u>Exercises</u>
 - Use bigger movements in real life situations outside of the treatment room assigned all 30 days

Practice using larger amplitude in functional tasks which are important to you!

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Samantha and Catherine provided more visual exercise examples,

Large Amplitude LSVT BIG Exercises



The next slide posed the question, how do the LSVT BIG Daily Exercises help you, and then provided examples,

- Starting and stopping movement when you want •
- Direction changes making turns
- Endurance or Stamina
- Balance
- Strength
- Range of Motion
- Posture

Samantha and Catherine explained the LSVT BIG Goal Generalization to functional activities in daily life!



Treatment Exercise: Rock and Reach (Helps to improve walking)



Treatment Goal: better arm swing and stability when walking dog



Plus... Practice











The best combination for success! You will always have - Lifelong Support After LSVT

The sit to stand video provided a visual on how to sit down in a

chair, then reach big and stand up. This can be incorporated

After treatment, take your daily dose of LSVT BIG homework exercises!

Daily exercise practice life-long

into you daily exercise regimen.

It was then stressed that,

- LSVT Homework Helper Videos
 - Purchase DVD or Download
- New Group Exercise Options!
 - LOUD for LIFE® and BIG for LIFE®
- Regular LSVT "Tune-ups" every 3-12 months
- Other enjoyable fitness for PD

At this point in the presentation, Molly took over to explain,

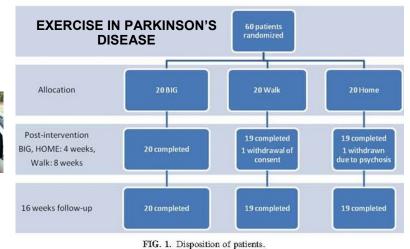
The Importance of Evidence Based Practice

- If you are investing time and effort into exercise and therapy, know the evidence and expected results
 - Has there been research? How do you know it works?
 - Are the results lasting?
- LSVT LOUD and LSVT BIG adhere to those principles of neuroplasticity and are supported by over 20 years of National Institutes of Health (NIH) funded research giving you confidence the treatments work!

Molly then provided the following information regarding the research on LSVT Big,

Comparing Exercise in Parkinson's Disease The Berlin LSVT BIG Study (2010, Movement Disorders)

Georg Ebersbach, 1* Almut Ebersbach, 1 Daniela Edler 1 Olaf Kaufhold,1 Matthias Kusch,1 Andreas Kupsch, and Jo"rg Wissel



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She added the following,

In a 2010 study by Ebersbach et al called the Berlin LSVT BIG study, researchers compared exercise in PD. 60 participants were randomized into 3 exercise groups: LSVT BIG exercise group (4 times/week x 4 weeks), Nordic walking group (2 times/ week x 8 weeks), and a Home Exercise Instruction group. All 3 groups received the same total number of hours of exercise. Participants then participated in a 16-week follow-up. The graph below depicts each groups progress during the 16-week period.

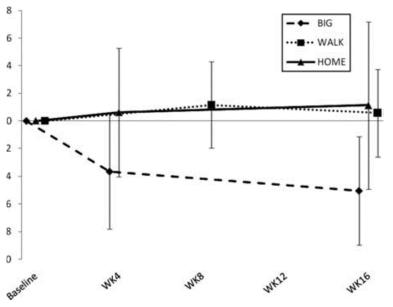


FIG. 2. UPDRS motor score (blinded rating), mean change from baseline (vertical bars 5 standard deviations). Change between baseline and follow up at week 16 was superior in BIG (interrupted line) compared to WALK (dotted line) and HOME (solid line), P <0.001. ANCOVA did not disclose significant differences between in intermediate and final assessments.

Molly explained that the BIG group was the only one to improve on the UPDRS (across the board) and amount of change per Dr. Ebersbach, is both clinically and statistically significant and on par with what they would expect out of a successful drug trial. She also supplied the following information regarding the rating scale used in this study. Unified Parkinson's Disease Rating Scale (UPDRS) is a rating scale used to follow the longitudinal course of PD. This particular study was looking at the UPDRS Motor Score, which includes items such as speech, facial expression, rigidity, coordination, agility, getting out of chair, walking, posture, and postural stability. Lower number = improvement in motor symptoms.

Molly then provided additional information from the study,

- Training amplitude enhances many levels of motor output
 Documented Cross-System Effects LSVT BIG
 - Trunk Rotation only improved for LSVT BIG
 - Stride length "Bigger steps", improved and maintained at 3 months
 - Speed improved and maintained at 3 months
 - Reaction Time improved (cued and uncued)
 - Motor score on Unified PD Rating Scale (UPDRS) improved
 - Balance, Coordination, Activities of Daily Living (ADLs) -

improved carryover to everyday living

 Dual Tasking - improved ability to dual-task Ebersbach et al 2010Ebersbach et al., 2013;

Farley et al 2008; Farley & Koshland, 2005; Fishel, et al., 2018; Isaacson, et al., 2018; Janssens et al., 2014; Millage, et al., 2017

With the next slide, Molly began explaining the benefits of both therapy and exercise,



How can both therapy and exercise help people with PD?

Here she provided information regarding research - Research on Exercise for \mbox{PD}

There are many types of exercise or therapy options that have been studied and/or recommended for people with PD. Examples:

- Treadmill training
- Dancing Tango
- Boxing
- Cycling
- Progressive Resistance Exercise
- Nordic Walking
- Tai Chi

Fisher et al, 2008; Miyai, et al., 2002; Jobges, et al., 2007; Lehman, et al., 2005; Hirsch, et al., 2003; Dibble, et al., 2006

Molly also stressed that, regular intensive exercise and activity is especially important, but it does NOT replace therapy and then she explained why:

- Not all types of exercise focus on AMPLITUDE. Amplitude focus is needed EVERY day due to small and slow movements seen in PD which affect everything one does.
- Not all exercise focuses on sensory awareness challenges. Recognizing you need to feel bigger in your movement than you think - just to move normally.
- Not all community-based exercise is personalized. Functional task practice in LSVT BIG is important for long-term carryover.

Molly then covered the best approach - Smart Solutions!



"Start as soon as possible after diagnosis, but it's never too late!"

Start with therapy first and then community-based exercise

- PD is COMPLEX!
 - LSVT BIG therapists will:
 - Help you to restore and optimize your function
 - Teach you what to do after treatment
 - Advise you on the best community-based exercise options

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- Teach you how to use your bigger movements in your exercise routines and recreational activities at home and in the community
- Make a lifelong partnership plan to keep moving well!

Molly offered the following analogy regarding the best approach:

You get your teeth cleaned and optimize the health of your mouth and then maintaining it on your own will be much easier! If it's been awhile since you've been to the dentist, you have to let the hygienist remove all the plaque and tarter first. Then they remind you how to brush and floss daily. If you never went to the dentist, it would be impossible to stay on top of things on your own without regular cleaning and checkups.

Molly then explained how to get started with LSVT BIG and LSVT LOUD,

- Ask your doctor for a referral and a prescription for a speech or physical/occupational therapy evaluation and treatment
- Visit www.lsvtglobal.com to find an LSVT LOUD or LSVT BIG Certified Clinician in your area
- Homework Helper Videos (DVD or Download)
 - 1 Helpful for daily practice during/ after LSVT BIG
 - 2 Standard and Adapted Versions

 Find in Amazon, LSVT Global store

Molly recommended four questions to ask any LSVT BIG or LSVT LOUD therapist,

- Do you deliver the gold standard dosage of LSVT LOUD or LSVT BIG? (4 days a week for 4 weeks, individual 60 -minute sessions, with daily homework and carryover assignments)
- 2. How many LSVT LOUD/LSVT BIG clients have you treated?
- 3. What are your typical outcomes?
- 4. Do you have a follow-up or maintenance plan for your clients?

It was then stressed that LSVT Global is a great resource for additional learning opportunities and information.



Opportunities to Learn More

- Monthly Webinars on Hot Topics!
- On Demand Webinar Library
- Patients & Family Section
- Featured Blog Articles, Testimonials, and Videos
- Live Seminars
- LSVT Global Facebook Page
- Ask our experts!



Molly provided the following summary and information about UC Health's Outpatient Rehabilitation,

- LSVT BIG addresses core symptoms which ALL patients with PD will experience (e.g. small movements, sensory mismatch)
- Intensive training and practice supported by research on motor learning and neuroplasticity (brain change)
- Standardized protocol, but can be individualized and adapted across disease severity and patient needs
- Short-term data support improvements in UPDRS and other measures of motor functioning
- LSVT Global offers training and certification for LSVT BIG and ongoing support for therapists and people with PD
- Contact Outpatient Rehabilitation at UCHEALTH: 719-364-4444 to schedule an evaluation

Molly then offered additional information,

- We currently offer LSVT BIG and LSVT LOUD at 2 of our UCHealth OP Clinics in Colorado Springs:
 - Our first location is at Printers Park Medical Plaza on S. Union Blvd. across from Memorial Park. We have 3 PTs who are certified in LSVT BIG and 1 SLP who is certified in LSVT LOUD.
 - Our second location is our Powers Clinic on Powers and S. Carefree. We have 1 PT who is certified in LSVT BIG and 1 SLP who is certified in LSVT LOUD.

This concluded the presentation, and the UC Health Team asked the attendees if they had any questions for them,

- 1. Can LSVT help with handwriting issues?
 - Yes, LSVT can help with handwriting.
- 2. Can you do LSVT Big and LSVT Loud simultaneously?
 - Yes, this is an option but most of the time they're separate.
- 3. When you do exercises at home, do they need to get faster?
 - After you are taught the exercises and practice them, you tend to get faster but, the focus is on form over speed.
- 4. Does treatment start at home or in a clinic?
 - Our treatment starts in an outpatient clinic.
 - Some home health care agencies can provide treatment in the home.
- 5. Could playing musical instrument be helped?
 - Yes, this could be one of your choices to work on with your therapist.
- 6. Is swimming good for Parkinson's?
 - Any exercise is beneficial.
 - Not any specific research related to swimming.
 - There have been 9 near drownings related to individuals that have had DBS.

Joe noted that you do not need a doctor's referral specific to LSVT Loud or LSVT Big, just a therapy referral.

Jill asked Zoom attendees to send their questions to her and she will forward to Joe and Molly for a response.

FIND IT ALL AT: WWW.LSVTGLOBAL.COM

Novel treatment using patient's own cells opens new possibilities to treat Parkinson's disease

Reprogramming a patient's own skin cells to replace cells in the brain that are progressively lost during Parkinson's disease (PD) has been shown to be technically feasible, reports a team of investigators from McLean Hospital and Massachusetts General Hospital (MGH) in the most recent issue of the *New England Journal of Medicine*.

PD is the second most common degenerative disease of the brain, and millions of people world-wide experience its symptoms, which include tremor, stiffness, and difficulty with speech and walking. The progressive loss of brain cells called dopaminergic neurons plays a major role in the disease's development. As described in the current report, the use of a patient's own reprogrammed cells is an advance that overcomes barriers associated with the use of cells from another individual.

"Because the cells come from the patient, they are readily available and can be reprogrammed in such a way that they are not rejected on implantation. This represents a milestone in 'personalized medicine' for Parkinson's," say senior author Kwang-Soo Kim, PhD, director of the Molecular Neurobiology Laboratory at McLean Hospital, the largest clinical neuroscience and psychiatric affiliate of Harvard Medical School.

The McLean-MGH team reprogrammed a 69-year-old patient's skin cells to embryolike pluripotent stem cells (called induced pluripotent stem cells) and then differentiated them to take on the characteristics of dopaminergic neurons, which are lost in Parkinson's. After extensive testing of the cells, Kim applied to the FDA for a single-patient, Investigational New Drug (IND) application and also received the approval of the hospital human subjects ethical review board to implant the cells into the patient's brain.

Bob Carter, MD, PhD, chief of Neurosur-

Science Daily, May 13, 2020

gery at MGH and co-senior author, says: "this strategy highlights the emerging power of using one's own cells to try and reverse a condition – Parkinson's disease – that has been very challenging to treat. I am very pleased by the extensive collaboration across multiple institutions, scientists, physicians, and surgeons that came together to make this a possibility."

In a series of two separate surgeries in 2017 and 2018 at Weill Cornell Medical Center and MGH, the patient underwent transplantation of the replacement dopamine neurons. Lead author Jeffrey Schweitzer, MD, PhD, a Parkinson's specialized neurosurgeon and director of the Neurosurgical Neurodegenerative Cell Therapy program at MGH, designed a novel minimally invasive neurosurgical implantation procedure to deliver the cells, working in collaboration with Carter at MGH and Michael G. Kaplitt, MD, PhD, a neurosurgeon at Weill Cornell.

Two years later, imaging tests indicate that the transplanted cells are alive and functioning correctly as dopaminergic neurons in the brain. Because the implanted cells originated from the patient, they did not trigger an immune response and were not rejected without the use of an immunosuppressant drug. Kim also noted, "We have shown for the first time in this study that these reprogrammed cells are still recognized as self by the patient's immune system and won't be rejected." These results indicate that this personalized cell-replacement strategy was a technical success, with the cells surviving and functioning in the intended manner. The patient has not developed any side effects, and there are no signs that the cells have caused any unwanted growth or tumors.

As for how the patients feels, in the time that has passed since surgery, the patient has enjoyed improvements in his day-to-day activities and reports an improvement in his quality of life. Routine

activities, such as tying his shoes, walking with an improved stride, and speaking with a clearer voice, have become possible again. Some activities – such as swimming, skiing, and biking, which he had given up years ago – are now back on his agenda. While it is too early to know whether this treatment approach is viable based on a single patient, the authors have the goal of continuing to test the treatment in formal clinical trials.

"Current drugs and surgical treatments for Parkinson's disease are intended to address symptoms that result from the loss of dopaminergic neurons, but our strategy attempts to go further by directly replacing those neurons," says Kim.

"As a neurologist, my goal is to make state-of-the-art treatments available to patients with Parkinson's," says Todd Herrington, MD, PhD, lead study neurologist at the MGH and Parkinson's expert. "This is a first step in developing this therapy. Parkinson's patients should understand that this therapy is not currently available and there is a lot of work still required to prove this is an effective treatment."

While there is optimism about the future of Parkinson's disease treatments because of their work, Schweitzer cautions against declaring victory against the disease. "These results reflect the experience of one individual patient and a formal clinical trial will be required to determine if the therapy is effective," says Schweitzer.

Because the patient had contributed funding to the team's research, the team extensively consulted with the MGH Institutional Review Board to discuss how to conduct this work ethically. "Ultimately everyone wanted to find a solution that safeguarded the patient's interests but allowed the field to benefit from the knowledge gained from his experience," said Dr. Schweitzer.



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

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DECEMBER 2020 & JANUARY 2021

PARKINSON'S PERSPECTIVE

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

Parkinson's Caregivers Support Group

Linda Marie is no longer able to head the caregiver's support group.

If you are interested in volunteering to lead this group, please notify Julie at <u>db_mgr@co-parkinson.org</u> or call

Ladies with Parkinson's Support Group

If you are a lady with Parkinson's Disease, and would like to join the group or just get more information, contact Carla Holland at contact Carla Holland or by email at president@co-parkinson.org.

Essential Tremor Support Group

For information on scheduled meetings and locations, please contact the POC listed below.

POC: Jim Sanchez ET Support Group Co-Leader 719-660-7275

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 John Farley by email: robun2good@gmail.com or Syble Krafft at (719) 488-2669.

Other Opportunities: Due to Coronavirus concerns, check ahead to see if canceled

LSVT BIG & LOUD at Home

At Home Healthcare offers the LSVT BIG & LOUD therapy program for individuals with Parkinson's Disease in the comfort of their homes. Their therapists are LSVT certified and can accommodate patients' home schedules. Medicare covers out patient therapy at 80% and home health therapy at 100%. If you have questions about this service or would like a referral coordinated through your primary care provider please call their office at:

Creativity Lab

Greetings everyone! With concerns for the health and safety of our participants, we at The Unsteady Hand have suspended all in person programing. We hope to resume around the first of the year. In interim, we are regularly updating our webpage with creative and fun things to do at home (Homework-the fun kind) and we also recently

created a PD resource page on our site. We miss you dearly and can't wait to see you again!

www.TheUnsteadyHand.org Re-Imaging Parkinson's - Mo

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. Therapy offered includes speech/ language & cognitive therapy, swallow rehabilitation and voice therapy (LSVT LOUD) an evidenced based voice treatment program designed for patients with Parkinson's disease. For more info, contact Jana Hothan, MA, CCC_SLP, LLC at slp@janahothan.com or by phone at (719) 338-8165.

Due Mber	 Charles Alvord Robin Alvord Christine Bishop Amy Coyle Pat Dashosh 	 Nicole de Naray Bruce Hughes Michelle Kahley Connie Kremer Steve Locke 	 Clayton McCoy Gregg Pinchuk James Rochon Ted Rudawsky Sue Seery 	 Mari Kay Shenk Sukey Skousen Charles Winkler Kristin Woestehoff
June 10 - 10 - 10 - 10 - 10 - 10 - 10 - 10	 Lisa Benhammou-Osur Doris Briggs Bill Byars Linda Byars Linda Christian Claudia Christiansen Vince Cologne 	 Hannah Duncan Elinor Edwards Laurie Fellabaum Sue Geist Kathy Heroux Bill Hicks Bob Meredith 	 Ronald Nickelson Lad Odell Alan Osur Mary Ellen Palmer Carol Prest Tom Prest Stanley Rapaport 	 Mary Roney Kathi Rudawsky Richard Sauvain Lonny Seery Larry Suhr Donna Telatnik
check BD listed "YES".	Christa Donley	 Randy Meyer 	 Jill Reid Committee Meetings 	February Newslette

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

December & January Executive Committee Meetings

Dec. 15th, 2020 & Jan 12th, 2021 @ 12:00 pm | Location: TBD Contact Linda at <u>secretary@co-parkinson.org</u> 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.

February Newsletter Input Deadline: January 22nd Call or e-mail Julie at:

db_mgr@co-parkinson.org.

...continued from page 2.

subjects to the protein alpha-synuclein and ascertained that the immune cells in the blood from Parkinson's patients are significantly worse at regulating the immune markers on the cell surface and that they are also less efficient to secrete anti-inflammatory molecules than the controls' cells.

"The immune system functions in a delicate balance. On the one hand, it cleans up invasive microorganisms and accumulations of unwanted proteins, such as alpha-snuclein, and does so by creating an inflammatory condition. But on the other hand, the immune system must also avoid damaging the body's own cells via too much inflammation, and apparently this balance goes awry in the case of Parkinson's disease," says Sara Konstantin Nissen.

She adds that in research circles it is believed that immune cells in the blood, which contain (or express) a certain receptor called CD163 on their surface, migrate into the brains of Parkinson's patients. It has been thought that the cells help to clean up the accumulations of the alpha-synuclein which damages the brain, but with the present study it is now suggested that the cells in question are already incorrectly regulated in the blood stream – before they reach the brain.

"This leads us to believe that it might be possible to, at the very least, slow down the degeneration of the neurons in the brain of Parkinson's patients by regulating the immune system with medicine." Says Sara Konstantin Nissen.

In addition to paving the way for supplemental medication for patients who have already been diagnosed with Parkinson's, Sara Konstantin Nissen also points out that the study suggests new ways of preventing or delaying the development of Parkinson's disease. This can be achieved by keeping a watchful eye on people who have an increased risk of developing Parkinson's disease, for example, those persons diagnosed with REM sleep behavior disorder (RBD), a disease where patients act vividly their dreams.

"Screening everyone for changes in the blood's immune cells would be pointless. However, we know that more than half of those who suffer from this sleep disorder, RBD, develop Parkinson's disease years later, so this is an obvious place to start. Other studies show that inflammation in the body can be reduced with exercise as a form of treatment, which can therefore reduce the risk of becoming ill at all. However, this requires a change of views among medical doctors and neurologists, because they will have to treat Parkinson's disease as more than just a brain disorder," says Sara Konstantin Nissen.

PD Exercise Classes: Due to Coronavirus concerns, check ahead to see if canceled

Ormao Dance Company Invites you to Dance for Parkinson's Live Streamed Class

Dance for Parkinson's-Keep Moving! Each Fri at 11am until further notice It's free and just requires internet access, a computer, iPad or smart phone to connect to the zoom website. There will be a new Zoom Meeting each week. Go to the https://co-parkinson.org event calendar each week for a new link. Contact Laura Treglia at 719-640-8478 for more information

Look forward to moving with you!

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 Max Capacity is offering PWR Boot Camp classes, donation based Power Punch Boxing, pole walking classes and individual PD specific fitness training. All PD Boxing classes and PWR BootCamp classes have moved to: 731 Iowa Ave. in Otis Park. 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. Tri-Lakes YMCA: PWR!Moves - Mon & Wed, 3 pm - 4 pm and Pedaling – Tues & Thur, 11:15 am - 12:15 pm Garden Ranch Y: PWR!Moves - Mon & Wed, 11:15 am - 12:15 pm; Fri, 1:10 pm - 2:10 pm Downtown YMCA: PWR!Moves - Mon & Wed, 1:15 pm - 12:15 pm For more info, call 719-329-7233 or email jclayton@ppymca.org Briargate YMCA: Ping Pong - Playing times are Monday, Wednesday and Friday from 1:30 to 3:30 pm. Come and join in the laughter and improve your skills. For more info contact Kristin Woestehoff, 719-648-9593 or kgwoestehoff@comcast.net Briargate YMCA: Boxing for Parkinson's - A non-contact boxing class based on a specific curriculum. Through rigorous exercise, emphasizing gross motor movements, balance, core strength and rhythm with positive impact on range of motion, gait, flexibility, posture and strength, this class should improve overall quality of life. The classes will be on Tuesdays & Thursdays from 12:30 - 1:30. \$5 for YMCA members and \$7.50 for non-members. For more info contact

Jamie Clayton at jclayton@ppymca.org.

NeuroRehab Project at ORA — Water and Movement Classes offers the following classes:

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.

Colorado Parkinson Foundation, Inc.

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

Parkinson's Perspective

DECEMBER 2020 & JANUARY 2021



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

- December 19th 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 – 11 am, Program: Parkinson's 101 – Speaker: Jill Reid
-
- ♦ CSPSG Caregivers meeting is the 3rd Friday of each month Contact Charlene at
- ◆ 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/coloradosprings-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.nwpf.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