



Living with Parkinson's Disease Symposium 2018







Centers of Excellence Network

Clarissa Martinez-Rubio, PhD

Better Lives. Together.

About the Parkinson's Foundation



The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience and passion of our global Parkinson's community.



Integrating the Mission





These guiding pillars of our work will allow us to take a chronic, degenerative disease and give people hope of independence and quality of life.

COE Network Today



45 Centers of Excellence setting expert Parkinson's care standards through a global network.

- 31 in the United States
- 14 international:

United Kingdom (2) Taiwan (1)

Netherlands (1 Australia (1)

Germany (1) Canada (6)

Israel (1) Singapore (1)

The network serves more than 100,000 people diagnosed with PD and provides:

Expert care

Support groups

Research

Education

Centers of Excellence - National



- * U. of South Florida, FL
- * Georgia Regents University, GA
 - * Emory University, GA
 - * U. of Kansas, KS
 - * U. of Iowa, IA * Cleveland Clinic, OH
 - * Baylor College of Med., TX
- * Oregon Health & Science U., OR

- * Johns Hopkins Med. Institute, MD
- * Massachusetts General Hosp., MA
 - * Beth Israel Deaconess Med., MA
 - * Struthers Parkinson's Center
 - * Beth Israel Med., NY
 - * New York University, NY
 - * U. of Rochester, NY
 - * Columbia University, NY

- * Medical University of South Carolina, SC
 - * Duke University, NC
 - * U. of North Carolina, NC
 - * U. of Pennsylvania, PA
 - * Vanderbilt University, TN
 - * Rush University Medical Center, IL
 - * Northwestern University, IL
 - * Barrow Neurological Institute, AZ
 - * U. of Southern California, CA
 - * U. of California, San Francisco, CA
 - * U. of California, San Diego, CA
 - * Parkinson's Institute, CA
 - * Georgetown University Hosp., DC
 - * U. of Florida, FL
 - * U. of Miami, FL





CENTER OF EXCELLENCE

Centers of Excellence – International



- * Victorian Comprehensive Parkinson's, Australia
 - * McGill Movement Disorders Clinic, Canada
 - * U. of Western Ontario, Canada
 - * U. of Calgary, Canada
 - * U. of Alberta, Canada
- * Pacific Parkinson's Research Centre, Canada
 - * Toronto Western Hosp., Canada
 - * Philipps University, Germany
 - * Tel Aviv Sourasky Med. Center, Israel
 - * Radbound U., Nijmegen, Netherlands
 - * National Neuroscience Institute, Singapore
 - * Taiwan University, Taiwan
 - * Kings College Hosp., UK
 - * Derby Hospitals U. of Nottingham, UK



The Network Expansion



28 applications received!

- 24 national and 4 international.
- Top 5 applicants were invited to submit a full application and host a site visit



Site Visits



Key components:

- 1. Application
- 2. Full day site visit
- 3. Patient panel (New)
- 4. Reviewers

Centers assessment:

Research, multidisciplinary patient care, outreach and education, and facility.



Published criteria & criteria-based evaluation

This process is performed every 5 years to all centers.

Site Visits: Identifying Excellence



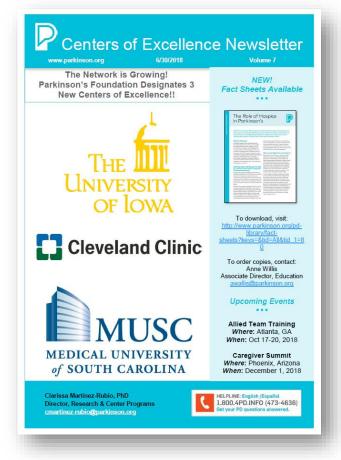
- Opportunity to meet the with multidisciplinary team
- Learn more about the innovative research conducted
- Meet the next generation of Parkinson experts – fellow
- Peer-to-peer learning
- Opportunity for the Centers to learn about resources and programs through the Foundation



Congratulations!!

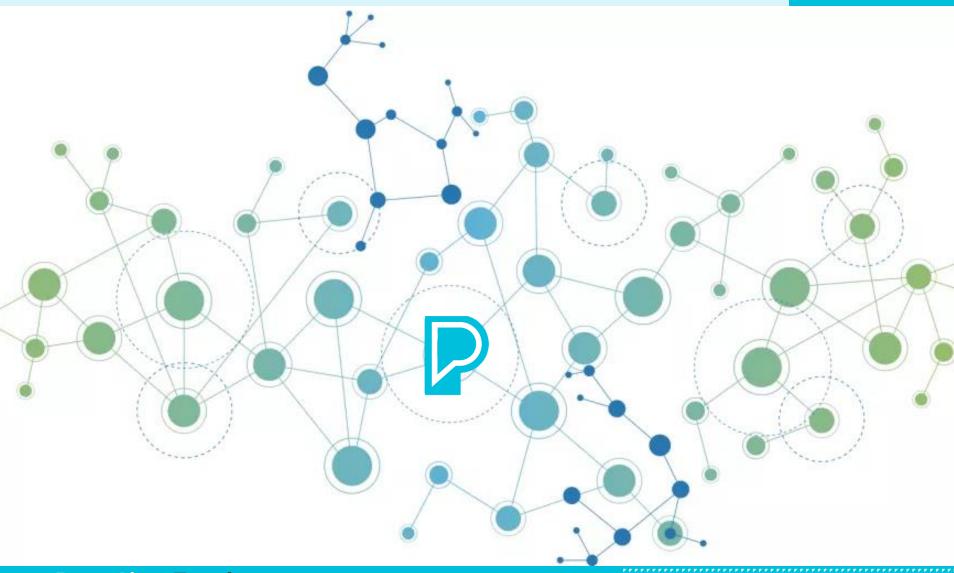






Propagating Excellence





Connect with Us - Thank you!







www.parkinson.org

1.800.4PD.INFO Helpline















Living with Parkinson's Disease: One prescription does not fit all

Vanessa Hinson, MD, PhD
Professor of Neurology
Director, MUSC PF Center of Excellence









Parkinson's Disease

- A diverse disorder
- No two people with PD are alike
- Certain commonalities











Parkinson's Disease facts

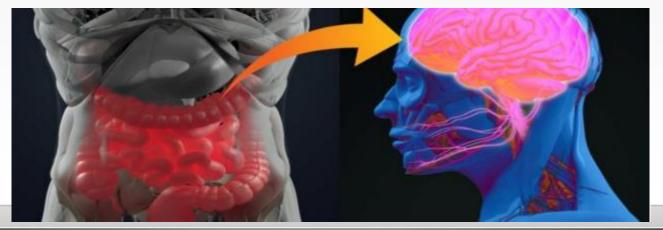
- 60,000 diagnosed in US every year
- 1 million people in US affected, 10 million worldwide
- 57,000 in tri-state area of SC,NC,GA (12,400 SC)
- Men 1.5X more likely to get PD
- Number of those diagnosed increases with age, regardless of sex
- Symptoms include: slowness, stiffness, tremor, soft voice, walking, balance and thinking problems

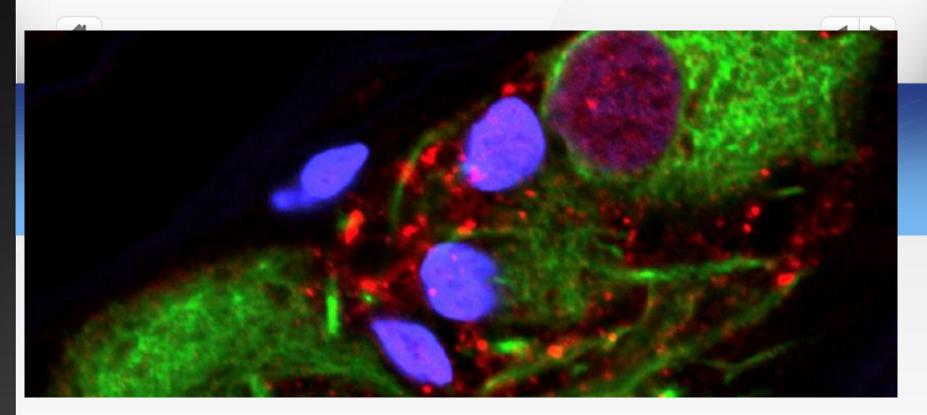


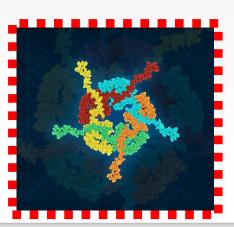


Parkinson's Disease facts

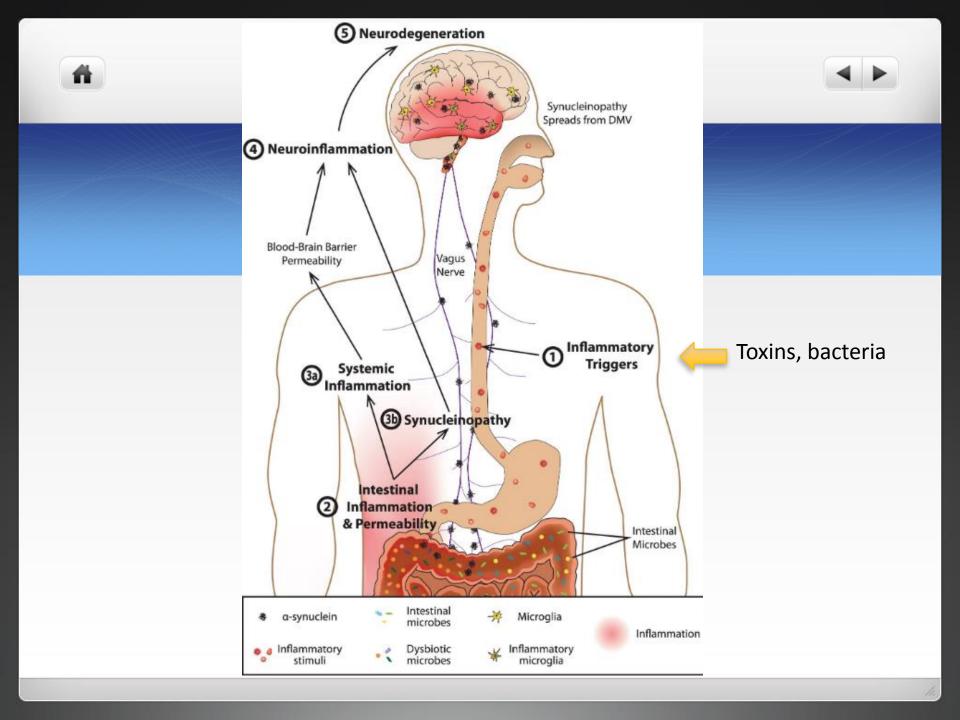
- Neurodegenerative brain disorder
- Combination of genetic and environmental causes
- Toxic protein alpha-synuclein misfolding and damaging brain cells
- Process starting in the gut, then via vagal nerve to brainstem and higher brain areas

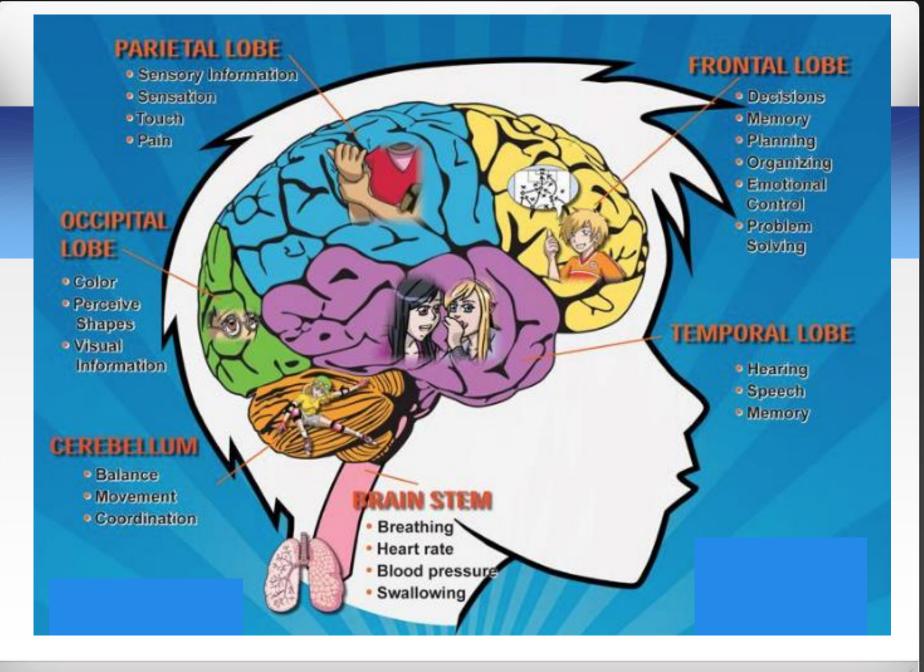






Confocal microscopyappendix









Parkinson's Disease



- Variability
 - Causation: genes, environment
 - Presenting /predominant symptom
 - Associated symptoms
 - Rate of progression
 - Role of race and sex





Causes: Genes

10 % of all PD cases: purely genetic 90 % sporadic

- Autosomal dominant: One altered copy of gene sufficient to cause PD. Rare: 1-2% of people with PD.
 - Examples: Alpha-synuclein (SNCA) and LRRK2
- Autosomal recessive: Two altered copies of gene required
 - Examples : PARK7, PINK1, PRKN.
- Risk factor modifiers genes: Modify the risk of developing PD
 - Example: GBA (most common gene mutation in PD)





Causes: Environment

- Head Injury
- Area of Residence
- Pesticides, Herbicides
- Welders (manganese)
- Factory workers with exposure to certain solvents





Potential protective factors

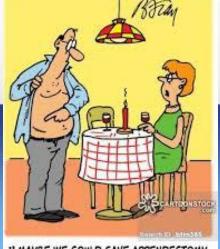
- Caffeine, nicotine
- Uric acid
- Anti-inflammatory Drugs
- Statins
- Physically demanding jobs
- Exercise
- Appendectomy







The Appendix story



"MAYBE WE COULD SAVE APPENDECTOMY SCARS UNTIL THE SECOND DATE!"

- Review of health records of 1,698,000 individuals in Sweden followed up to 52 years (91,888,589 person-years) + PPMI data
- Goal: determine PD risk with and without appendectomy
- Risk of PD was decreased by 19.3% in appendectomized individuals
- Significant delay in age of PD onset in individuals with an appendectomy

The vermiform appendix impacts the risk of developing Parkinson's disease

Bryan A. Killinger^{1,5}, Zachary Madaj^{1,5}, Jacek W. Sikora², Nolwen Rey^{1,3}, Alec J. Haas¹, Yamini Vepa¹, Daniel Lindqvist^{4,5}, H...

+ See all authors and affiliations

Science Translational Medicine 31 Oct 2018.





Does it matter how I got my PD?

• Genes:

- Parkin: younger onset, more dyskinesia and dystonia, less cognitive impairment, longer time to DBS
- GBA: akinetic rigid, higher rate of cognitive decline, shorter duration to DBS
- SCNA: less tremor, more rapid progression
- LRRK2: less rapid progression, less dyskinesias
- PINK1: more depression, anxiety



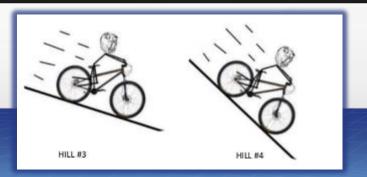


Tremor/no tremor Does it matter?



- Tremor predominant PD
 - less loss of dopamine neurons
 - better cognitive performance
 - relatively slow disease progression
- Tremor may be result of a different brain process than other PD symptoms
 - tremor does not progress at the same rate
 - tremor can occur on the body side contralateral to the most affected side
 - tremor responds less well to dopamine treatment than slowness and stiffness

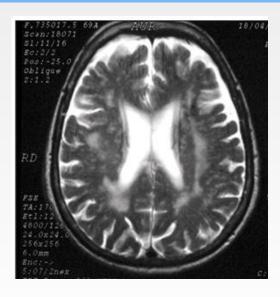






Factors influencing rate of progression

- Genotype
- Phenotype: Tremor versus non-tremor, soft voice versus strong voice <u>Beach Party</u>
- Co-existing vascular disease:
 - gait impairment
- Role of race and gender?
- "Behavior"---exercise---mental engagement



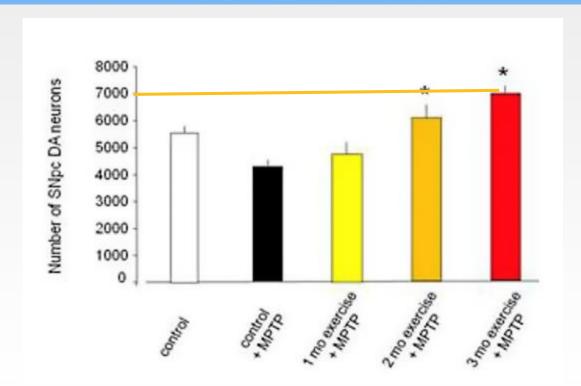


Exercise: Is it a neuroprotective and if so, how does it work?



Michael J. Zigmond a, *, Richard J. Smeyne b

Exercise and disease progression animal studies







What happens at the brain level with exercise?

- Increased energy production
- Increased antioxidant defense
- Reduced inflammation



- Newly created connections between brain cells
- Increased brain protective factors (BDNF, GDNF)









JAMA Neurology | Original Investigation

Effect of High-Intensity Treadmill Exercise on Motor Symptoms in Patients With De Novo Parkinson Disease

- 128 people with untreated PD within 5 y of diagnosis (40-80y)
- Not exercising at baseline
- High intensity (treadmill 4 d /week 80% max heart rate), moderate intensity, no exercise groups-----6 months exercise
- High intensity exercise group progressed much slower than no exercise group





Influence of gender Why are women at reduced risk for PD?

Environmental factors

 Women are less likely than men to be exposed to pesticides and heavy metals, or to sustain a head injury.

Biological factors

- There may still be undiscovered biological differences between women and men that increase the likelihood of Parkinson's.
 - Women who had had removal of their ovaries before menopause have a greater risk of PD (rises to that of men).





Symptoms reported most frequently differ

Research suggests that women more often experience large swings in symptoms from even small changes in medications or schedules.

- Women have an 80% increased risk of experiencing wearing off of both motor and non-motor symptoms.
- Dyskinesias (Involuntary movements) are the most frequently reported side effect by women with Parkinson's.





Treatment women receive differs

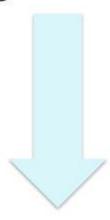
Women with Parkinson's who receive DBS are reported to have greater gains in quality of life than men.

However, women are less likely to receive DBS for treatment of Parkinson's disease.





Most Likely to see a Neurologist for Parkinson's



Least Likely to see a Neurologist for Parkinson's White Men (55.1%)

Hispanic Men (51.5%)

Asian Men (50.0%)

Hispanic Women (47.4%)

White Women (46.7%)

Black Women (45.4%)

Black Men (44.7%)

Willis, A. et al. Neurology. 2011





Racial differences Study: African-Americans half as likely to be diagnosed with PD as whites

- Pennsylvania Medicaid claims data: identify newly diagnosed PD among the 182,271 enrolled adults age 40–65
- 4-year cumulative incidence of PD was 54 per 100,000 among whites, 23 per 100,000 among African-Americans
- African-Americans were four times less likely than whites to receive any PD treatment
- Biological versus cultural explanation?

Mov Disord. 2009 Racial Differences in the Diagnosis of Parkinson's Disease Nabila Dahodwala, MD et al.





One prescription does not fit all Treatment choices based on symptoms

- Functional impairment yes/no
- No: Research ---- exercise
- Yes: Symptomatic treatment ----exercise
- Symptomatic treatment:
 - Tremor predominant versus slow/stiff
 - Gait impairment
 - NOH, dysphagia, cognitive impairment, hallucinations
 - Advanced therapies : Duopa, DBS







Summary PD is not a single disease

- PD syndrome
- Variety of shades
- Common themes
- But many differences
- Approach to treatment customized

having a choice is better than not having a choice







Panel discussion: "This is how I manage my PD"

Allan Keener, Christina Press, Hubert Yarborough, Dr. Nathan Rowland, Dr. Marian Dale





Q&A







Break



Coping with a Chronic and Progressive Illness: Parkinson's Disease

Lacey Clement, Ph.D. Leah Boepple, Ph.D.

Behavioral Medicine Department of Psychiatry and Behavioral Sciences Medical University of South Carolina

November 10, 2018

Impact of a Chronic Illness

The Patient

Initial Impact:

- Shock
- Denial
- Loss and grief
- Anxiety and depression

Must adjust to:

- Symptoms of the disease
- Stress of Treatment
- Feelings of vulnerability
- Threat to self-esteem
- Financial Concerns
- Changes in family structure

Impact of a Chronic Illness

The Family

Must adjust to:

- Increased stress
- Change in the nature of the relationship
- Change in family structure/roles
- Lost income

- Different issues for different relationships
 - Adult children of ill parents
 - Spouse of ill person



Chronic Illness as a Crisis

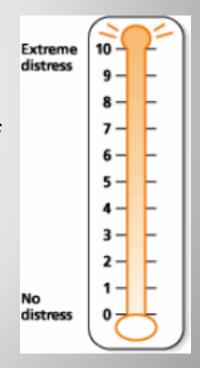
- Turning point in an individual's life
- Disruption to established patterns of personal and social functioning
 - Disequilibrium
- Finding new ways of coping

Living with Parkinson's Disease

- Motor
- Non-motor
- Loss of control
- Fear of the Unknown

Recognizing Distress

- How do you know when you're stressed?
 - Stress symptoms can include:
 - Feeling sad, blue, down, or depressed
 - Feeling disinterested or having a lack of motivation
 - Worry, anxiety, nervousness
 - Frustration, irritability, and anger
 - Social isolation



Building Stress Resistance

- Personal control and responsibility
 - Changing thought patterns
- Positive health habits
- Take breaks
 - Activity Pacing
- Social support
- Relaxation

Recognizing Unhelpful Thinking

- All or Nothing Thinking
- Mind Reading
- Fortune Telling
- Mental Filter



Relaxation Exercises

- Diaphragmatic breathing ("belly breathing")
 - Slow down and deepen breathing
 - Helps to activate your nervous system's relaxation response and improves breathing control

Imagery

- Engage all 5 senses!
 - See
 - Hear
 - Touch
 - Smell
 - Taste





Living a Meaningful Life

- What is important to you in life?
- How does your current life align with your values?
- What can you do TODAY to make your life more meaningful and value-driven?

Need additional support?

- Local and/or online support groups
- Seek out a local psychologist or counselor
- Speak with your MUSC provider about referral to the Behavioral Medicine clinic

MUSC Behavioral Medicine 843-792-0686

Myths & merits of alternative therapies

Christine Cooper, MD

Disclaimer:

- "Alternative therapies" treatments that are thought by someone (sometimes only the creator of said therapy) to be helpful for specific conditions, but generally do not have solid, peer-reviewed scientific evidence to back the claims.
- My recommendations on the following slides are based on scientific evidence alone. I fully acknowledge that large knowledge gaps in science exist.
- Please use common sense when considering these options:

AVOID if it can hurt you PHYSICALLY or FINANCIALLY

Hands-on therapies & activities

- Assisted stretching



- Tai Chi **✓ Merit**
- Mindfulness & meditation

 \(\square
 \) Merit





Supplements

• B12 and vitamin D **/Merit**



* Only if blood levels low

· "neuro" supplements





· Curcumin and turmeric



Fish oil



• CBD oil



Mind games and vibration

• Luminosity, crosswords, sudoku, socialization / Merit

Whole body vibration





Vibration shoe



? T.B.D.

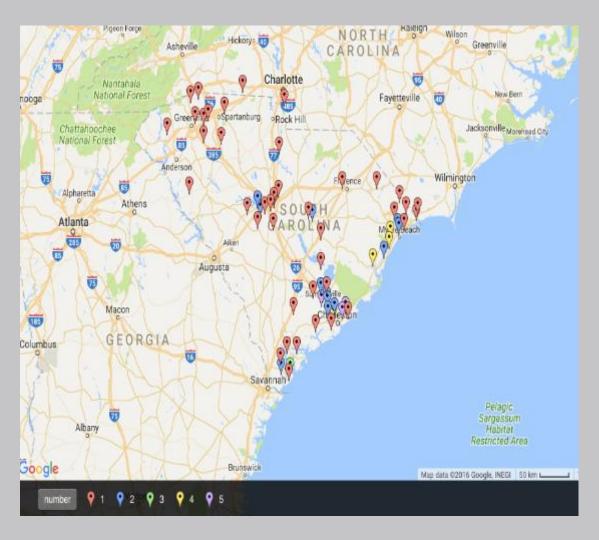
Infusions



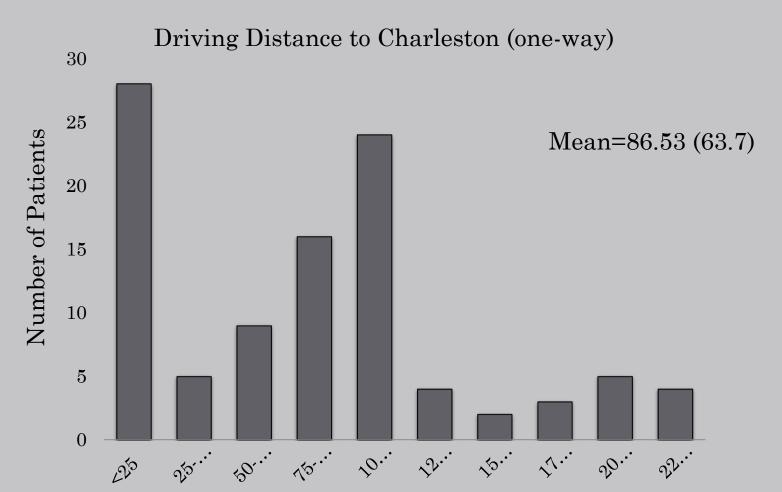
Telehealth

Dr. Travis Turner

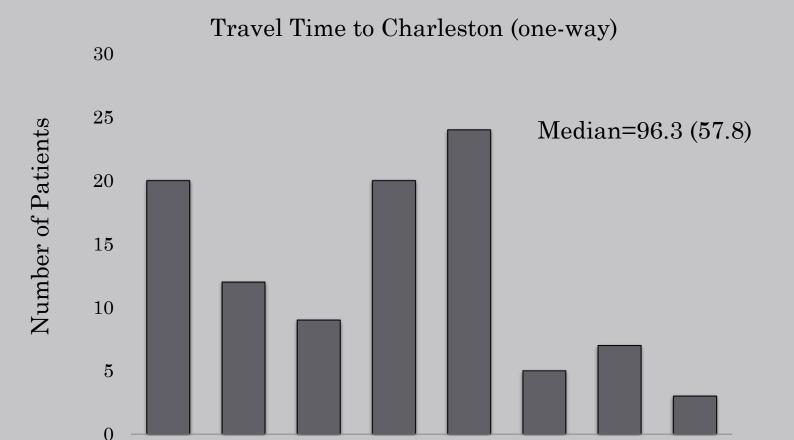
Movement Disorders Neuropsychology: 100 consecutive referrals in 2016



Movement Disorders Neuropsychology: 100 consecutive referrals in 2016



Movement Disorders Neuropsychology: 100 consecutive referrals in 2016



Minute

90-120

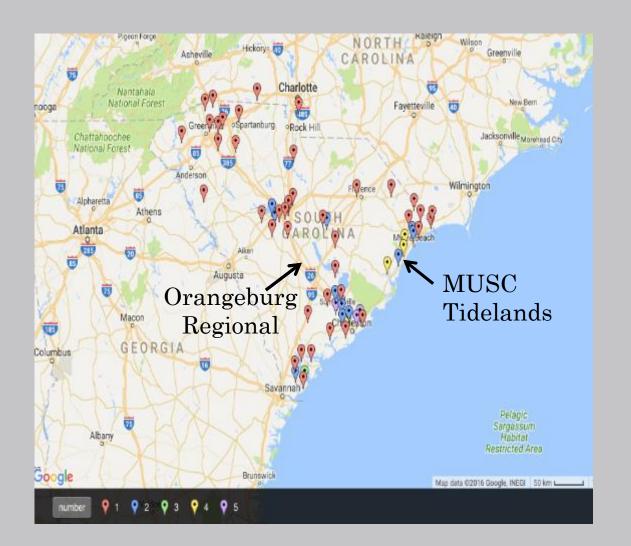
120-150 150-180 180-210 210-240

<30

30-60

60-90

MUSC Outpatient Clinics



Common tele-health questions

- Will my insurance cover the visit?
- Are there any procedures that can't be done via telehealth?
- I love having my vitals taken before seeing the doctor. Will I miss out on this fun if I do tele-health?
- Is someone there to provide help if needed?
- Are neuropsychological evaluations done by telehealth reliable and valid?
- What does a telehealth visit look like?









Parkinson's Disease Research at MUSC

Shonna Jenkins Clinical Research Manager, MUSC



OF WEIKNEW WHAT IT
WAS WE WERE DOING,
IT WOULD NOT BE CALLED
RESEARCH, WOULD IT?
ALBERT EINSTEIN
Quotes Everlasting.com

If at first you don't succeed, search, search again. That is why we call it research.

PD Research: MUSC Movement Disorders Program

- Our Start
 - Murray Center: June 2003
- Our Growth
 - Affiliated with Parkinson Study Group (largest non-profit network of PD centers in North America) and Michael J. Fox Foundation (funded more than \$750 million towards PD research since 2000)
 - Funded PD Trials
 - o 20 trials in less than 5 years
 - o More than \$4 million in PD research funding over the last year alone
 - Recruitment, Enrollment and Retention
 - 80% of trials exceeded enrollment goal
 - Approximately 150 patients enrolled in currently open studies
 - Retention rate close to 98%
 - Parkinson's Foundation Center Of Excellence: 45 world-wide including 31 in the USA
- Our Future

Treat. Stop. Cure. Prevent.

PD Research: WHAT is it and WHY is it Necessary

o WHAT:

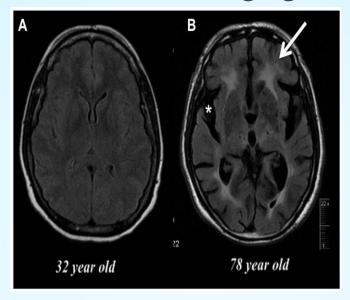
- Investigation
- Drugs/devices
- Not for "guinea pigs"

o WHY:

- Excellent care
- o It takes a village
- o Means to an end

Small vessel disease in Parkinson's disease

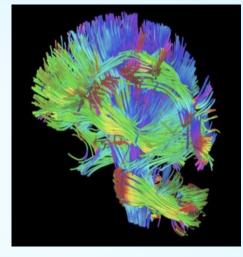
• In mid-late life, most of us show evidence of "aging" in the brain, which is seen on brain imaging.



- The exact cause of these changes is not clear.
- Possible causes include genetics, blood pressure changes, diabetes, cholesterol, environmental exposures, and diseases.

Small vessel disease in Parkinson's disease

- This study will investigate the role of these brain changes on Parkinson's disease symptoms using brain imaging and blood tests.
- One study visit
 - Brain MRI
 - Clinical evaluation
 - Brief cognitive testing
 - Electronic walkway analysis
 - Blood draw





• This study may help us <u>explain some of the variability in PD</u> symptoms between individuals AND <u>provide us with a new areas to intervene in PD symptoms and progression.</u>

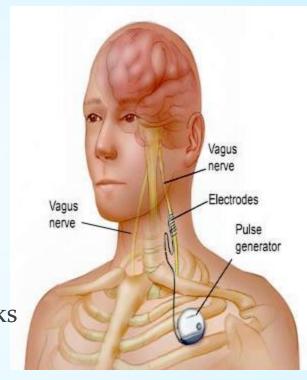
Transcutaneous Auricular Vagus Nerve Stimulation (a.k.a taVNS)

 Looking at the effect(s) of taVNS on motor function, cognition and biomarkers

Non-invasive

Cutting edge

Visits: 5 days a week for two weeks





- ONLY neuroprotective trial for folks with moderate to advanced PD
- Diagnosis date on or before 11/10/2013
- Otherwise healthy
- 13 visits over 8-9 months
- Several slots left!

UP-AND-COMING

- SPARK (otherwise known as the "vaccine" trial)
 - aim is to STOP progression
 - diagnosis date within 3 years of screening visit
 - no dopaminergic therapy

PRESENCE

- test drug's ability to improve cognition
- designed for folks with moderate problems in thinking, memory and daily living skills

How Can I Find Out what Studies are Available?

*MUSC Website

 http://academicdepartments.musc.edu/neurology/research/ Murray Center/

South Carolina Research Website

http://scresearch.org

❖ Fox Trial Finder

https://foxtrialfinder.michaeljfox.org

❖ Clinical Trials.gov

https://clinicaltrials.gov

MUSC Point of Contact

 Shonna Jenkins: Email (<u>jenkisho@musc.edu</u>); Phone: 843-792-9115

Research at MUSC MDP: Meet the Staff

- Dr. Vanessa Hinson: MDP Program Director
- Dr. Gonzalo Revuelta: MDP Assistant Program Director; DBS Program Director
- Dr. Christine Cooper
- Dr. Marian Dale
- Dr. Federico Rodriguez-Porcel
- Dr. Shabbir Merchant
- Dr. Travis Turner: neuropsychologist
- Dr. Colin McLeod: MD fellow
- Dr. Emmi Scott: neuropsychology fellow
- Tracy Millman: nurse (DBS coordinator)
- Shonna Jenkins: research coordinator
- Danielle Helms: research coordinator
- Tim Sheehan: research coordinator





Q&A







Lunch+Expo

1pm Eve Hiott and Friends: Shag dancing demo





Exercise Demo: Get Excited and Move Kathy Cromwell



FALL PREVENTION

Victoria Wilson, PT, DPT

Medical University of South Carolina

LEARNER SHOULD...

Identify

Prevent

Understand

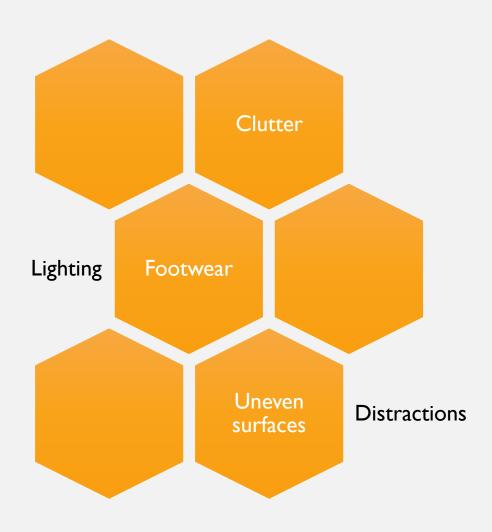
WHY ARE YOU FALLING?

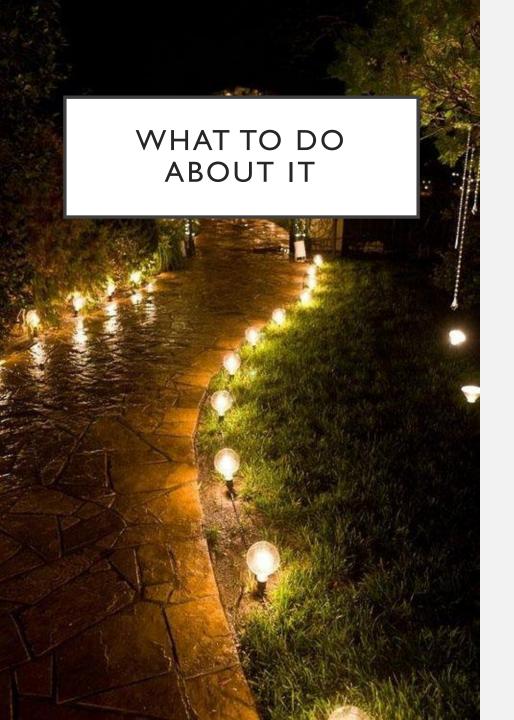


EXTERNAL CAUSES

When the environment contributes

CAUTION





- Remove rugs
- Relocate cords
- Decrease multitasking
- Light the path
- Choose supportive, well-fitting shoes

PARKINSON'S DISEASE

Disease specific causes of falls

INTERNAL CHANGES

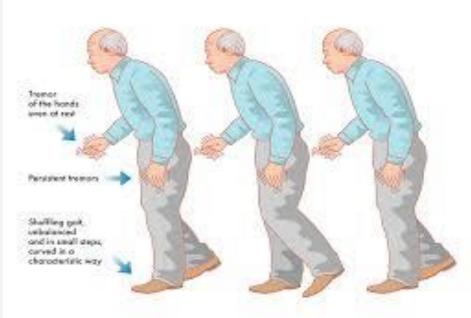
PARKINSON'S DISEASE

- Body awareness
- Freezing
- Shuffling
- Stiffness
- Lack of balance reactions
- Impaired coordination
- Slowed reactions
- Decreased step height

OTHER CAUSES

- Weakness
- Vision changes
- Dizziness

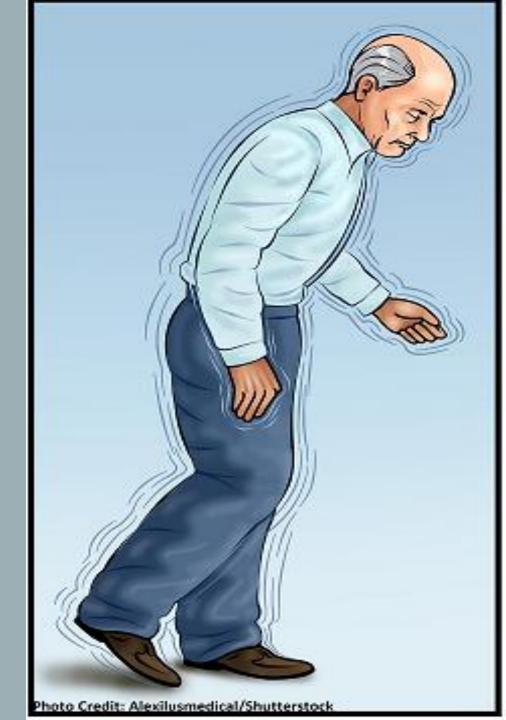






https://www.youtube.com/watch?v=zeGXCILfc
nM

WHEN ARE YOU FALLING?



NOT JUST WALKING...

During turns

i.e. to sit down

During transfers

Sit to stand

When distracted

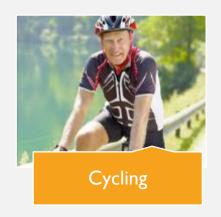
Two tasks

THERE IS GOOD NEWS!

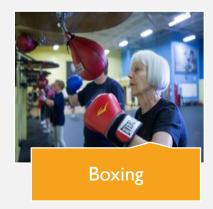
EXERCISE

Exercise has been shown to prevent falls and decrease overall disability in PD in conjunction with appropriate medicines

WHAT IS THE BEST KIND?















HOWEVER...

Most studies include exercise prescribed by an exercise professional or physical therapist

WHEN TO SEEK HELP FROM A PT?

EARLY IN PD

- To begin a structured exercise program
- To prevent future imbalance
- To promote flexibility

LATE IN PD

- To provide strategies to prevent falls
- To promote maintained mobility
- To compensate for poor balance

TREATMENT

TRAINING

- Doing two things at once
- Learning to stop a fall
- Increasing flexibility
- Increasing physical fitness

STRATEGIES

- Cane
- Walker
- Avoiding distractions
- Visual and verbal cueing

REFERENCES

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- McGough E, Robinson C, Nelson M, et al. A Tandem Cycling Program: Feasibility and physical performance outcomes in people with Parkinson's disease. J Neurol Phys Ther. 2016; 40(4) 223-9.
- Sherrington C, Michalef Z, Fairhall N, et al. Exercise to prevent falls in older adults: an updated systematic review and meta-analysis. Br J Sports Med. 2017; 51: 1749-57.





Caregiving Panel

Mary-Ellen Jenney, Regina Herman, Dr. Kirsten Mohn, Amy Delambo





Q&A







Living with Parkinson's Disease Symposium 2018



