Aware in Care:
Getting the Best Parkinson's Care When You Are in the Hospital

August 24, 2019

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Parkinson's Foundation

Aware in Care

Parkinson's Foundation

Why Are We Here Today?

- To help people affected by Parkinson's:
  - Understand the risks associated with hospital stays.
  - Get tools to play an active role in their care.
  - Be prepared for a hospital visit, whether planned or unplanned.
  - Develop strategies to get the best possible care in the hospital.
- To be *Aware in Care*.

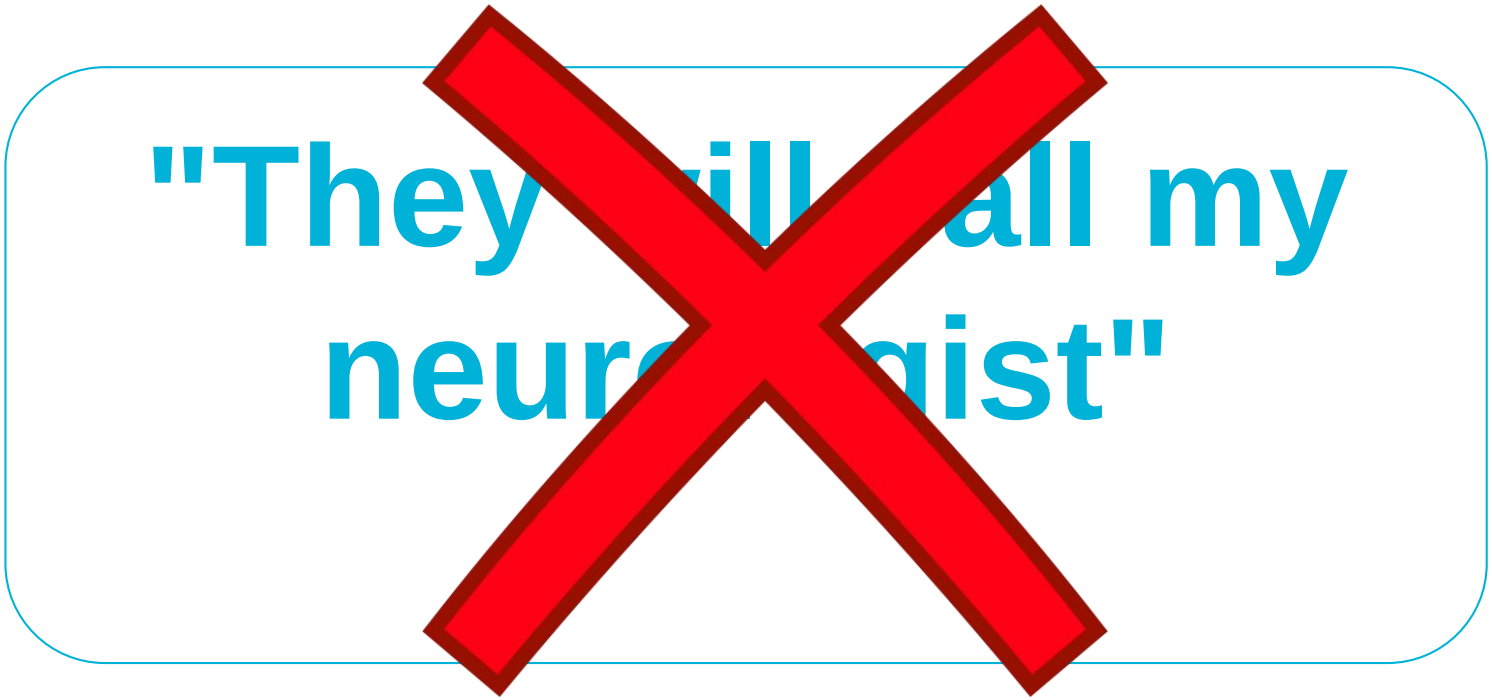
Aware in Care
Parkinson's Foundation

Care Transitions: Hospital to Home

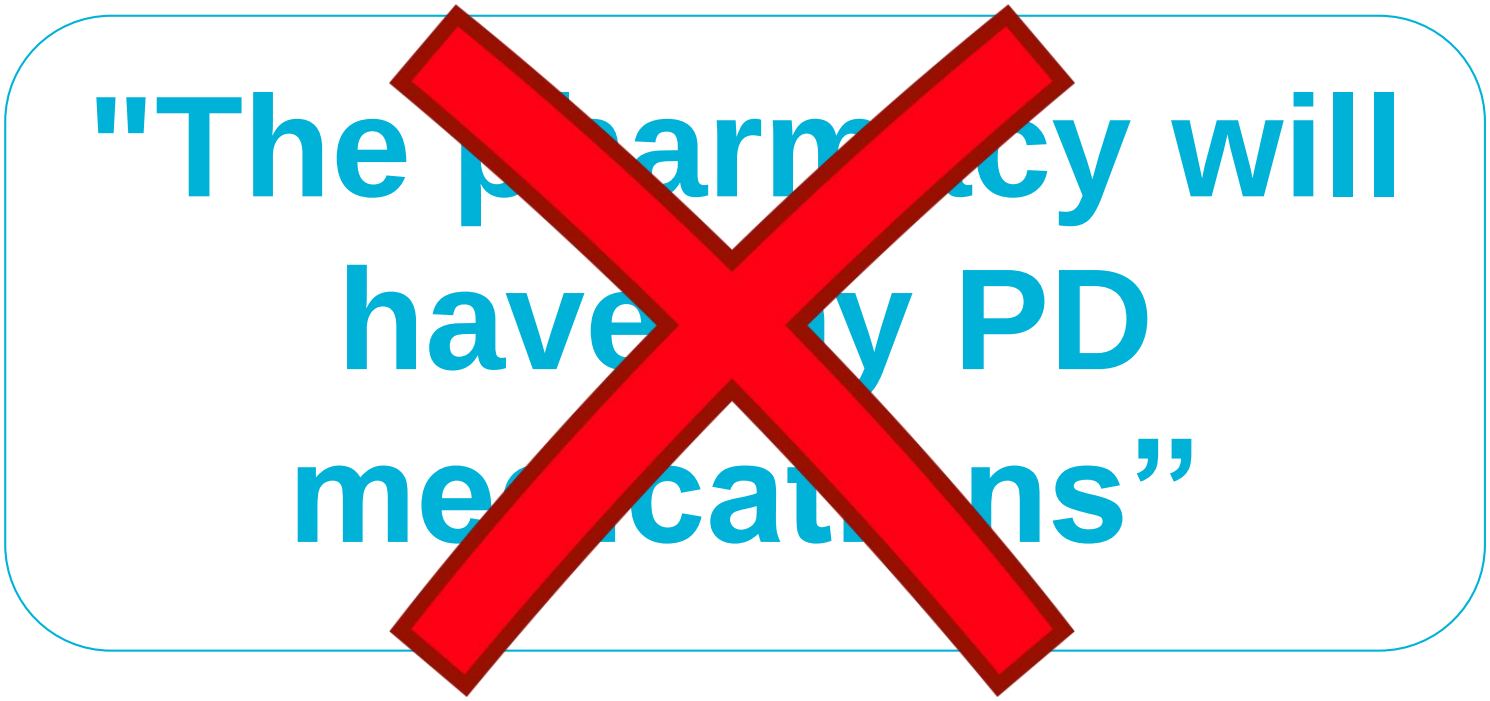
- For most people, the transition from hospital to home is the challenging part.
- For people with Parkinson's, it's the reverse.

Hospitals are safe, right?

True or False



True or False



True or False

"Not all staff understand the symptoms of PD."

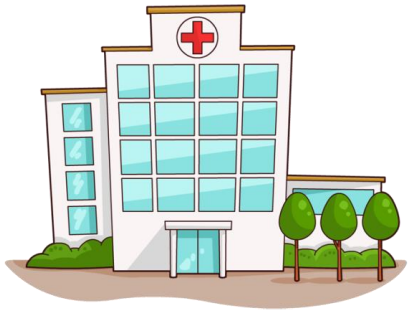
True or False

"They will give me my medication on time."

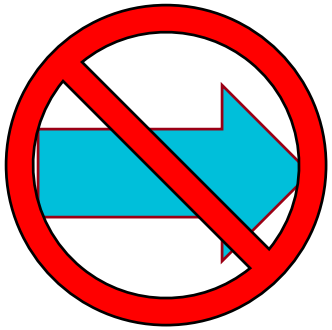
True or False

Parkinson's and Hospitalization

1 in 3



3 in 4



2 in 3

100 patients
33 admissions
25 Medications changed
16 complications

MJ Aminoff, et al. *Parkinsonism and Rel. Disord.* 2011. 17:139-145. KN Magdalinou, et al. *Parkinsonism and Rel. Disord.* 2007 Dec;13(8):539-40. OHH Gerlach, et al. *BMC Neurol.* 2012.

The Frightening Truth…

People with PD in the hospital have a 1 in 4 chance of complications <u>because of medication errors</u>

The Reality

- People with Parkinson's are hospitalized 44% more than their peers without Parkinson's.[1]
- People with Parkinson's suffer avoidable complications at a higher rate than non-PD patients.[1,2,3]
- This yields longer hospital stays than non-PD patients.[1,3]

1. Aminoff MJ., et al. Parkinsonism and Related Disorders, 2010.
2. Derry CP, et al. Postgrad Med J., 2010. 86 (1016): 334-7
3. Guttman M, et al. Movement Disorders, 2004 19(1):49-53.

Why Is This Happening?

Even in the best hospitals, there can be a lack of understanding of Parkinson's disease.

Non-PD specialists may not be fully aware of the critical importance of Parkinson's medication timing.

Hospital pharmacies may not stock all PD medications.

Hospital staff may not know that many common medications can be unsafe for people with Parkinson's.

Why Is This Happening?

Only 25% of hospitals have a mechanism in place to contact a person's Parkinson's doctor upon admission.

70% of hospital staff are unaware of the drugs that worsen PD motor symptoms or are contraindicated for people with Parkinson's.

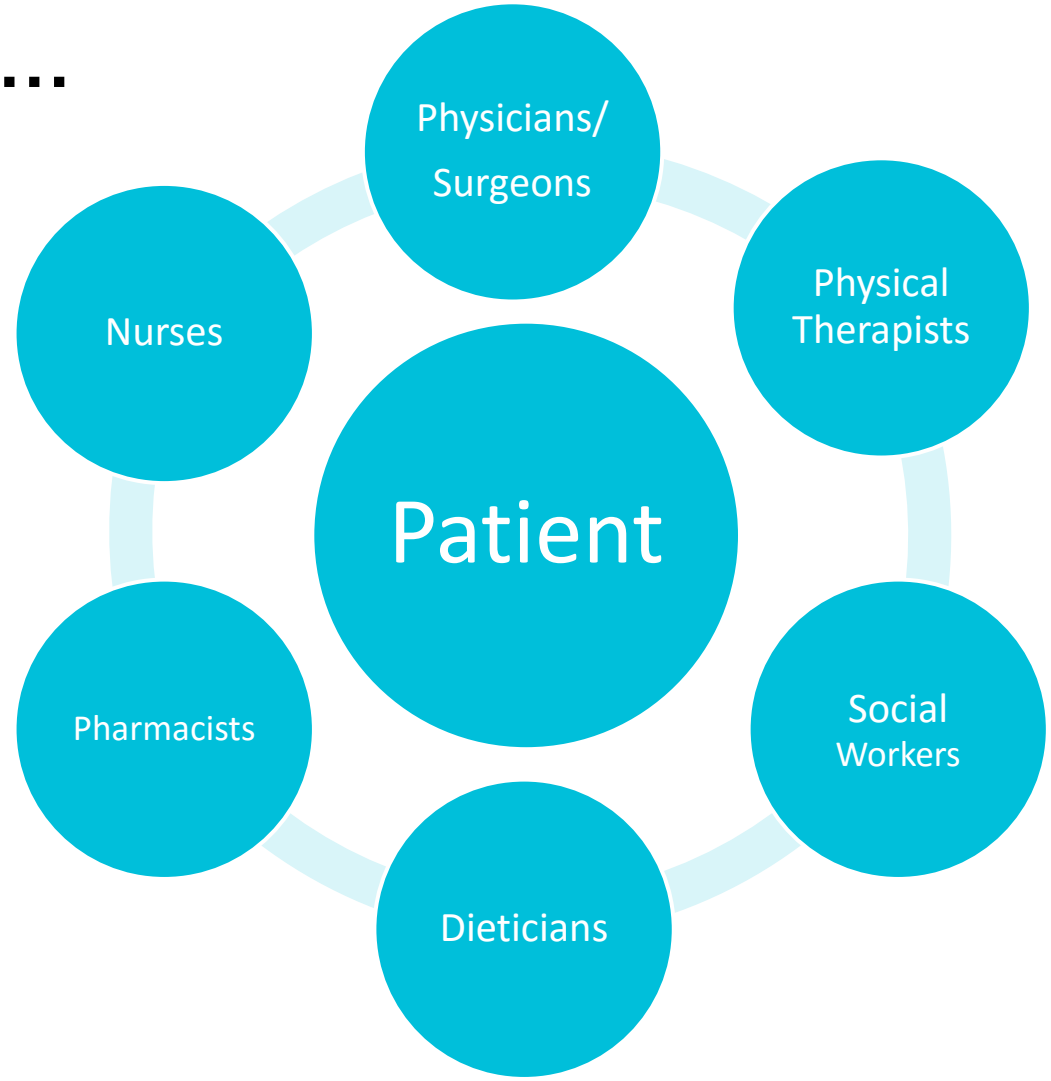
Chou, Kelvin L., et al. Best Care Practices in NPF Centers: Care of the Hospitalized Parkinson's Disease Patient. Parkinsonism and Related Disorders, 2011.

Lack of Awareness…

- Of the **critical importance** of Parkinson's medication timing.
- That many common medications for pain, nausea, depression and psychosis are **unsafe** for people with Parkinson's.
- That **poorly managed Parkinson's** might result in mental confusion and other serious symptoms.

Hospitals Can Be Complicated

Many providers…



Medication Challenges

Multiple medications are used to treat Parkinson's.

Contraindicated medications are not often recognized.

Changes in times/dosing of medications can affect patient status.

Compromised swallowing ability may dictate a change in medication formulation.

Mobility Challenges

PD patients should mobilize as early and as often as conditions allow.

Ambulation reduces chance of worsening rigidity and associated symptoms.

PD patients are at heightened risk for falls.

Patients and care partners should discuss risks associated with lack of movement with the doctor and physical therapists.

Role of Patient and Care Partner

Each person with PD has the best knowledge of their disease and other conditions.

Each person with PD has a unique combination of medications and listed regimen.

Each person with PD is most knowledgeable about their own special needs but may have communication challenges.

Care partners can have all of the above information and advocate for the Parkinson's patient.

Changing Outcomes

The right* medications, on time

No contraindicated medications-

Never Haldol

Aware in Care Is Here to Help

The Parkinson's Foundation's *Aware in Care* campaign can help EVERYONE be better informed:

- **Person with Parkinson's**
- **Care partner and family**
- **Healthcare providers**
- **Hospital/facility staff**

The *Aware in Care* kit helps patients and families plan for a hospital visit and advocate for the best possible care during the stay.

What's in the Kit?

What's in the Kit?

1. **Kit Bag:** Along with *Aware in Care* materials, pack your bag with your current medications and supplements in original bottles.
2. **Hospital Action Plan:** Read about how to prepare for your next hospital visit, whether it is planned or an emergency.
3. **Parkinson's Disease ID Bracelet:** Wear your bracelet at all times in case you are in an emergency situation and cannot communicate.
4. **Medical Alert Card:** Fill in your card with emergency contact information and place in your wallet.

What's in the Kit?

5. **Medication Form:** Keep this form up-to-date and make copies. You can print additional copies from **parkinson.org/awareincare**.
6. **Parkinson's Disease Fact Sheet:** Share the facts about Parkinson's with hospital staff and ask that a copy be placed in your chart.
7. **"I Have Parkinson's" Reminder Slips:** Share vital information about Parkinson's disease with every member of your care team in the hospital.
8. **Magnet:** Use this magnet to display a copy of your Medication Form in your hospital room.

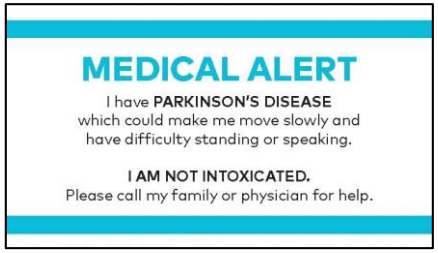
Take Action at Home

Step 1: Line Up Help

- Assemble your care team – care partner, Parkinson's doctor, primary care physician.
- Who else is part of your care team? Identify those professionals, family or friends who may be active in your care.

Step 2: Pack Your *Aware in Care* Kit

- Review materials and know what's in the kit.
- Add an **emergency contact list**, an extra supply of your Parkinson's medications, a completed **Medication Form**, and a copy of your healthcare proxy card.



Take Action at Home

Step 3: Prepare for the Unexpected

- Wear your **Parkinson's ID Bracelet.**
- Put the **Medical Alert Card** in your wallet.
- Establish an emergency plan and share it.

Step 4: Find a Good Hospital

- Contact your local hospital(s) and ask questions.
- If your community has multiple hospitals, select one that will best meet your needs as a person with PD. These websites may be helpful:
  - www.qualitycheck.org/consumer
  - www.hospitalcompare.hhs.gov

Take Action in the Hospital

Step 5: Be Vocal

- Use the **Parkinson's Fact Sheet** and "**I Have Parkinson's" reminder slips** to educate staff about Parkinson's.
- Let them know you need your Parkinson's ***medications on time, every time!***
- If you have trouble speaking, ask your care partner to speak up on your behalf.

Step 6: Be Persistent

- Talk to each member of your care team about your symptoms and special needs.
- Ask for help if you feel no one is listening.

Take Action in the Hospital

Speak up if you think something is wrong!

Step 7: Get Moving

- Start moving as soon as possible after your procedure.
- Ask for physical therapy in the hospital.
- Find out if you qualify to receive physical therapy at home once you are discharged.

Step 8: Stay on Top of Your Care

- Engage your care partner in monitoring all aspects of your care.
- Pay attention to the medications, treatments and tests you receive in the hospital.
- Ask about medications that may be unsafe for people with Parkinson's.

Take Action at Home

Step 9: Follow Up and Provide Feedback

- Contact your Parkinson's doctor and share your discharge instructions.
- Contact the hospital and let them know about the quality of care they provided.
- Prepare your kit for your next hospital stay.

Step 10: Connect with Others

- Reach out to join a local support group.
- Need a local referral?
  Call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636).

When Should I Use the Kit?

Planned Hospital Stay

- Bring it with you for every physician or consult appointment.
- Pack and bring the kit with you when you go to the hospital.

Emergency Visit

- Ask a family member or friend to bring your packed kit to the ER.

Annual Check-Up with Your Parkinson's Doctor

- Bring the kit with you, and share the program with your doctor at your next scheduled appointment.
- Exposure to the kit will help medical professionals become familiar with the materials and special considerations PD patients may need in the hospital.

Aware in Care is a national campaign to:

- Prepare and empower people with Parkinson's disease, through tools and information, to be your own advocate in the hospital setting, and an engaged partner in your healthcare overall.
- Educate healthcare providers and staff to help people with Parkinson's get the best possible care while in the hospital (or other inpatient setting – rehab, LTC, etc).

Aware in Care
Parkinson's Foundation

Aware in Care Is Made Possible by…

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…And individuals like you. Thank you for your support.

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What We Do

For Today
Improving care for everyone living with Parkinson's disease

For Tomorrow
Advancing research toward a cure

For Us All
Building on the energy, experience and passion of our global community

Parkinson's Foundation

Get Involved: Find Us Near You

Parkinson's Foundation
Ohio

Parkinson.org/Ohio

Phone: (614) 890-1901

Email: ohioinfo@parkinson.org

Visit our website to sign up for our Newsletter!

Parkinson's Foundation

Advanced Care Planning:
Communicating Your Care Decisions and Wishes

Making the Patient's Voice be Heard

Lynda Anello
Community Liaison
VITAS Healthcare

VITAS® Healthcare

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Objectives

By the end of this presentation you will be able to:

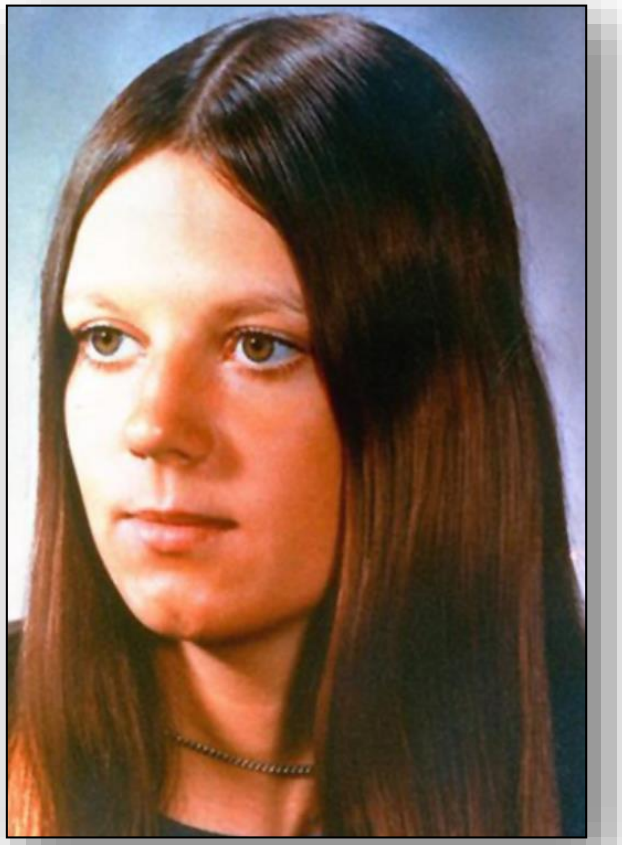
- Review the origin and meaning of advance directives
- Define advance care planning (ACP)
- Identify the types of advance directives and their function
- Provide guidance and resources on advance directives

A Little Background

- End-of-life issues: patient autonomy, quality of life at the end of life, and withdrawal of life-sustaining treatments
- In 1990, Congress enacted the Patient Self-Determination Act:
  - Accept a patient's right to either refuse or accept medical treatment
  - Safeguard the patient's autonomy and preserve self-determination
  - Protect patients against maltreatment
  - Foster communication between patients and their physicians
  - Protect physicians from litigation in end-of-life decision making

A Little Background (Cont.)

Karen Ann Quinlan



Nancy Cruzan

Terri Schiavo

Advance Directives

- Advance directives are legal documents that allow the patients to formally state their choices regarding what actions should be taken for their health in case they are no longer able to make decisions for themselves because of illness or incapacity
- Advance directives were developed to provide a practical process for ensuring patient autonomy at the end of life, giving a voice to the patient's preferences for medical care within the spectrum of reasonable clinical options

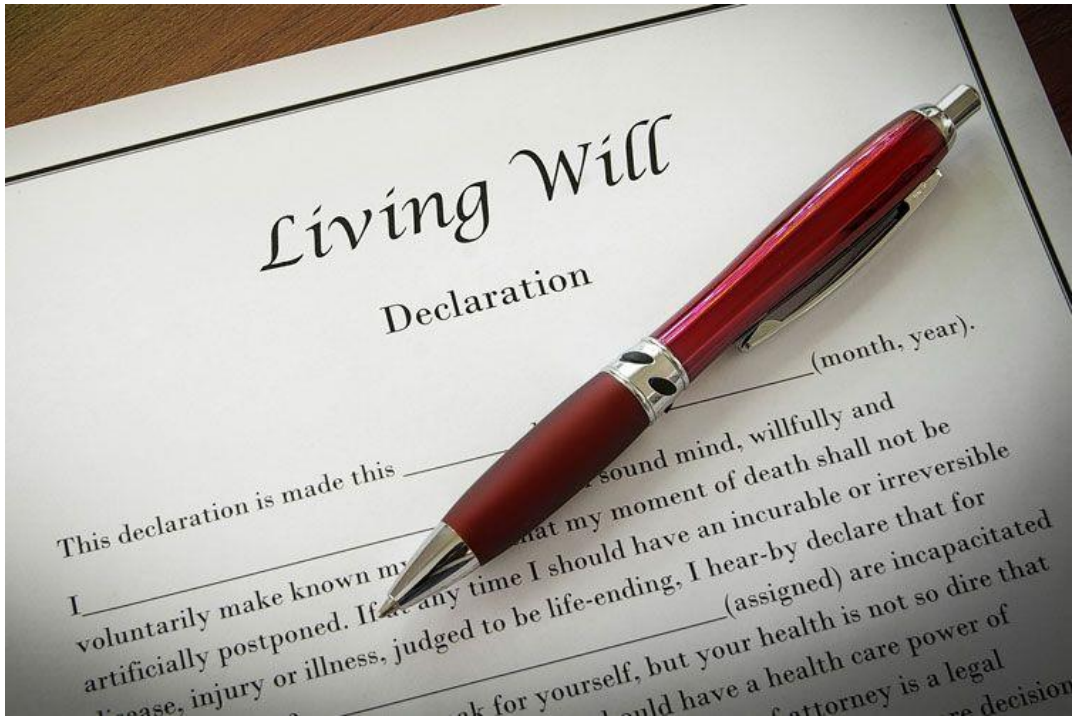
Advance Directives (Cont.)

- **The two most common types of advance directives are:**
  - The Living Will
  - The Durable Power of Attorney for Health Care
- **Advance directives are not an end in themselves**

  They are most effective when incorporated into a comprehensive advance care planning process, which helps identify what course serves the patient best and then outlines specific steps to make that course more likely

The Living Will

- A Living Will is a document designed to control certain future health care decisions only when a person becomes unable to make decisions and choices on their own
- The person must also have a terminal illness or permanent unconsciousness
- The living will describes the type of medical treatment the person would want or would not want in these situations



The Living Will (Cont.)

- The living will can describe under what conditions an attempt to prolong life should be started or stopped, including treatments such as:
  - Dialysis
  - Tube feedings
  - Artificial life support
- It can also include:
  - “Do not resuscitate” orders
  - Whether patients want to donate their organs or other body tissues

Healthcare Power of Attorney

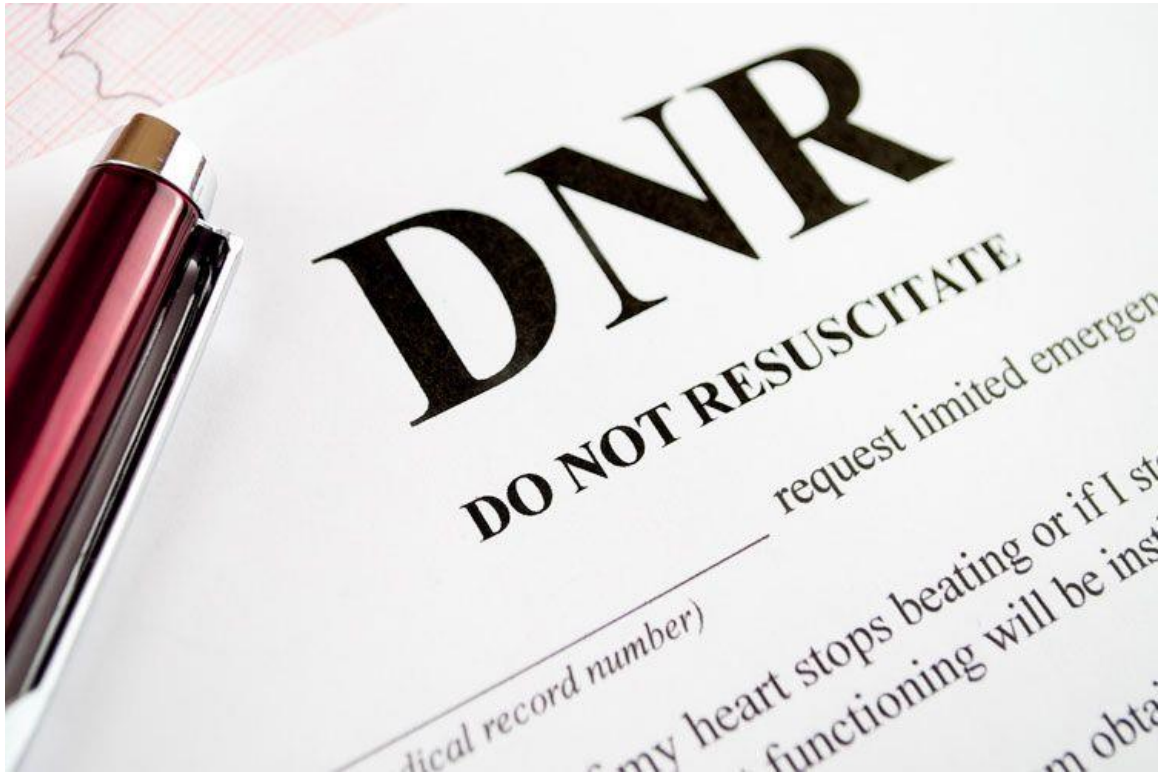
- A durable power of attorney for health care is a legal document in which patients name a person to be their proxy (agent) to make all their health care decisions if they become unable to do so
- The patient's proxy can speak with all caregivers on their behalf and make decisions based on directions they gave earlier
- If the patient's wishes in a certain situation are unknown, the proxy will decide based on what he/she thinks the patient would want

Healthcare Power of Attorney (Cont.)

- The person named as the patient's proxy or agent should be someone the patient trusts to carry out his/her wishes
- The patient should name a back-up person in case the first choice becomes unable or unwilling to act on his/her behalf
- The law doesn't allow the agent to be a doctor or a nurse providing health care to the patient unless he/she is a close relative
- Most state laws require requests for a proxy to be in writing

"Do Not Resuscitate" Orders

- Resuscitation means an attempt by medical staff to restart the patient's heart and breathing, such as CPR
- In some cases they may also use life-sustaining devices such as breathing machines
- A "Do Not Resuscitate" or DNR order means that if the patient stops breathing or his/her heart stops, nothing will be done to try to keep him/her alive



CPR Facts - What you should know

- CPR does not help as much as most of us think
- CPR works best if:
  - You are healthy with no illness
  - It can be given to you within a few minutes of when your heart or lungs stop working
- CPR does not work as well if:
  - You have chronic health problems
  - You have an illness that can no longer be treated
  - You are older and weak

What to do with Advance Directives

- Make sure that the patient's health care provider, attorney, and the significant persons in his/her life know that he/she has an advance directive and where it is located – the patient may also want to give them a copy
- Have the conversation – find opportunities, create opportunities
- Update over time if health or other circumstances change
- An advance directive needs to be either notarized or witnessed by two individuals - at least one of the witnesses cannot be a spouse or a blood relative

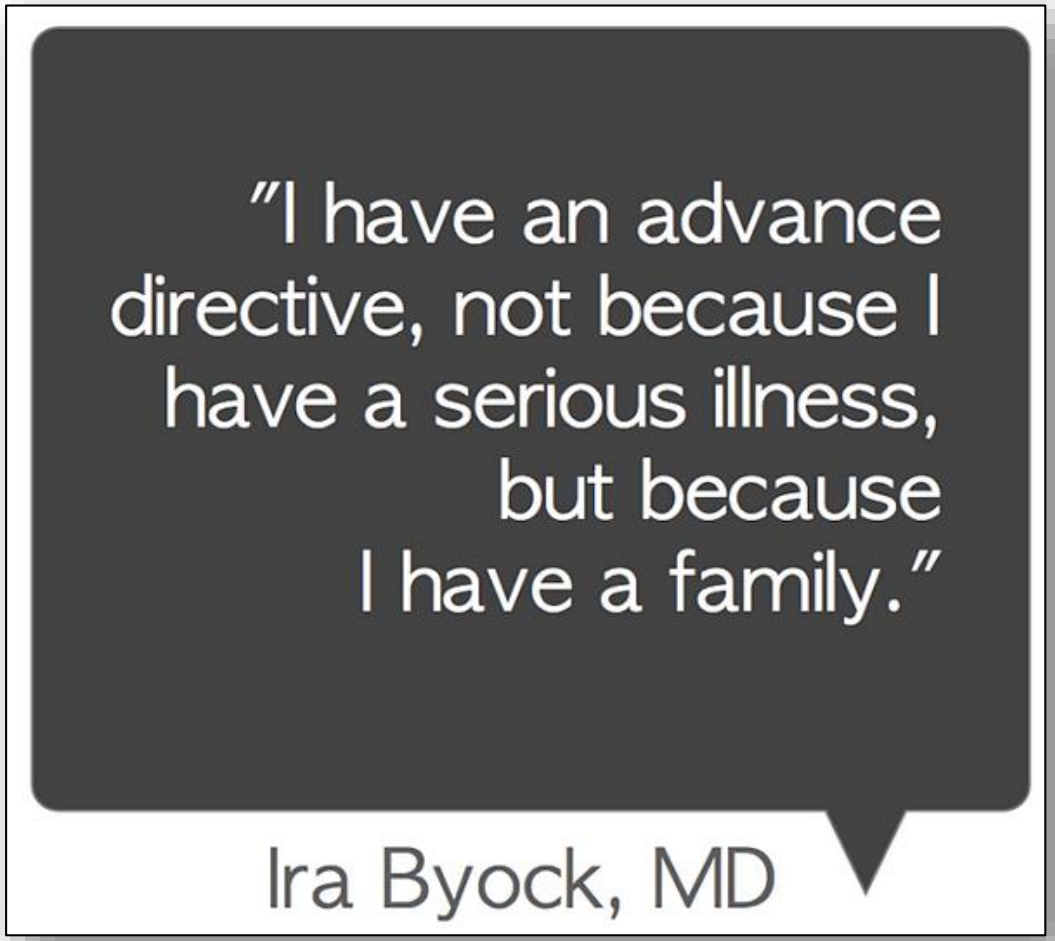
Advance Directives and Hospice

- A DNR is not required in order to receive hospice care
- Hospice staff will discuss the importance of advance directives in preserving patient choice
- VITAS offers training on advance directives and assistance with having the conversation

Patients and End-of-Life Care

- As people age, consideration should be given to their treatment wishes in the event that they lose the ability to manage their care
- A large discrepancy exists between the wishes of dying patients and their actual end-of-life care
- Frequent clinician–patient conversations about end-of-life care values, goals, and preferences are necessary
- **Most patients say they look to their clinicians and other health care providers to initiate the discussion**

Closing Thought



Questions

References

Byock, I. (2013). *The best care possible: A physicians quest to transform care through the end of life*. New York: Avery/Penguin Group (USA).

- CPR Facts: Materials Developed by Respecting Choices®

MC750-E_CPRFacts_v9.15

- www.gundersenhealth.org/respecting-choices

Advance Directives and Advance Care Planning

Making the Patient's Voice be Heard

Welcome to the

Educational Symposium

A free educational event for patients, families, and caregivers

Saturday, August 24, 2019

UC Health IN SCIENCE LIVES HOPE.

University of Cincinnati
Gardner Neuroscience Institute

Thank you to our Breakfast and Lunch Donors:

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Thank you to our Exhibitors

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- **Adamas Pharmaceuticals**
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- **Impax Specialty Pharmaceuticals**
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- **NeuroRehab and Balance Center**
- **Parkinson Community Fitness**
- **Parkinson's Foundation Ohio**
- **Parkinson Support and Wellness**
- **Parkinson's Snowflake Project**
- **Senior Lifestyle**
- **Social Security Administration**
- **Sunovion**
- **UC Health Gardner Center**
- **UC Outpatient Therapy**
- **Vertical Neuroscience**
- **Vitas Healthcare Corporation**

Reminders

- Visit our Exhibit Area for helpful, informational handouts

- Restrooms
  - Men's/Ladies & Family restrooms located in hallway outside the doors.
  - Because we have such a large group, we cannot have set break times. Please feel free to come and go as needed.

Reminders

- Questions for the final panel discussion
  - Fill out index cards at your table
  - Turn in at the registration desk by noon
  - We will collate all the questions and try to answer as many as possible during the panel discussion
- Lunch will be served at 11:35 a.m.
- Kindly turn off or silence your cell phone

Before You Leave Today

- Evaluations Forms are available online! After the symposium, please go to this link to give us your feedback:

  https://www.surveymonkey.com/r/2X7WKL5

- In the coming weeks, videos of the lectures can be viewed online at:

  http://UCHealth.com/parkinsons

The UC Gardner Center for Parkinson's Disease and Movement Disorders

A team of health care professionals dedicated to providing the optimum and most up-to-date treatment and research opportunities for individuals dealing with Parkinson's disease and other movement disorders

Complementary Alternative Medicine & Nutrition in Parkinson's Disease

Cara Jacob, MD
Assistant Professor of Neurology
University of Cincinnati
Gardner Neuroscience Institute

CAM & Nutrition in PD

- Common question from patients with PD
  - Other than medication what can I do to help my symptoms?

CAM in PD

- Complementary Alternative Medicine:
  - "Natural" Products: Herbal supplements, neutraceuticals, vitamins, minerals
  - Mind/body practices: Meditation, Massage, Acupuncture, Exercise

CAM in PD

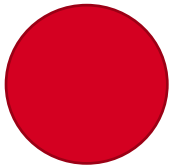
- 40%-75% of PD patients surveyed reported use of CAM
- What is the draw?
  - Sense of control/empowerment over one's own well-being
  - More holistic/natural approach
  - Mistrust of conventional/western medicine

CAM in PD

- What is the evidence for CAM?
  - Many patients surveyed report improvement with use of various CAM
  - ?Placebo effect
  - Few trials of CAM have been done in a randomized, double blinded, placebo/controlled fashion (the "gold standard") for clinical trials
  - Remember, not everything that gains attention in the press has been backed by research and not all research is good research

CAM in PD

- Rating system:



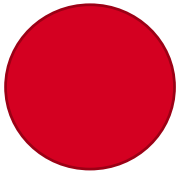
Well designed clinical trials with many patients have been done and have shown no benefit in PD or no clinical trials have been done showing any benefit.

Studies have been done which may show benefit but results have not been replicated or studies were poorly designed/had very few patients. More studies need to be done to prove/disprove benefit.

Well designed trials have been completed showing benefit in PD with large number of patients.

CAM in PD

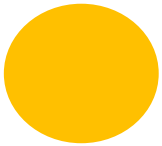
- **Vitamin E, CoEnzyme Q10, Inosine, Creatine**
  - Despite well designed clinical trials, these products have failed to show improvements in Parkinson's symptom or slowing of progression

Rating: 

CAM in PD

- **Mucuna Pruriens**
  - Legume from India, levodopa extracted from the roasted seeds in powder form
  - Handful of small studies showing benefit with mucuna in motor symptoms of Parkinson's
  - Downside: Tolerability was issue in one study, no regulation of dosing/potency so you don't know what you are getting
  - Rating:

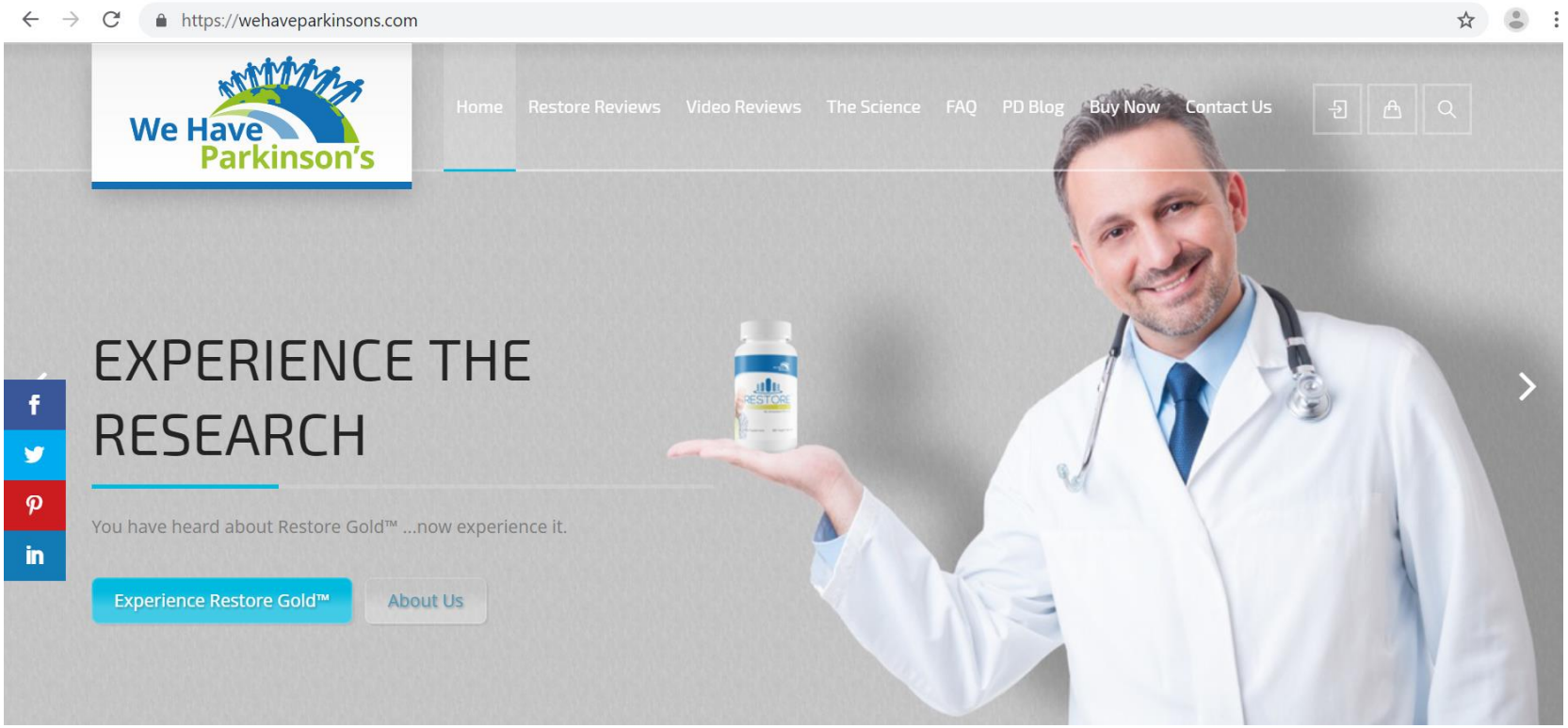
CAM

- **Thiamine (vitamin B1):**
  - Recent internet buzz
  - Single small study performed by group in Italy
    - PD patients given 100 mg thiamine intramuscularly twice weekly
    - All patients with significant improvement in PD motor scores
    - No control group
    - Patients increased levodopa during study (mean at baseline 180 mg levodopa, at 2 months 515 mg levodopa)
    - Rating: 

CAM in PD

- **Restore Gold**
  - Ingredients: Acetyl-L-Carnitine, Alpha Lipoic Acid, Grape Seed Extract, Green Tea Extract, L-Tyrosine, N-Acetyl-Cysteine (NAC), Tauroursodeoxycholic acid (TUDCA)
- Claims:
  - Slows progression of Parkinson's disease
- Reality:
  - Not true. There have been zero studies showing this medication is effective or safe.

CAM in PD



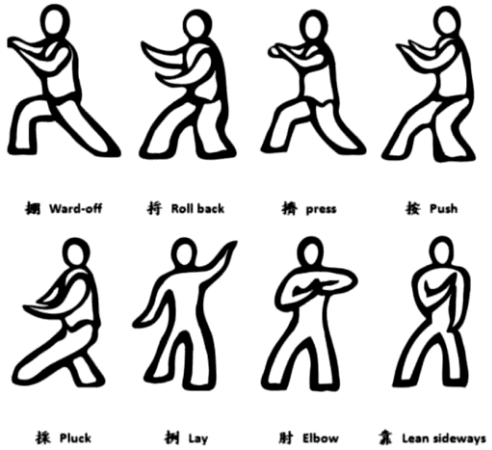
Rating:

CAM in PD

- **Marijuana/CBD oil (Cannabidiol)**
  - Despite much public interest in Marijuana/CBD in PD only handful of studies have been done with mixed results
  - Only 2 of those studies have been randomized, double blinded, placebo controlled (gold standard study)
  - Neither study showed improvement in motor symptoms or dyskinesias in PD
  - Not regulated

- Rating:

CAM in PD



- Tai Chi
  - Traditional Chinese martial art
  - Uses flowing movements and postures alongside deep breathing/meditation
  - Felt to improve balance, stress, strength, and overall health
  - Several randomized controlled trials in PD
  - Largest study 195 subjects did Tai Chi or conventional resistance training or stretching exercises
  - Over 6 months, all groups showed improved motor function, but Tai Chi group performed significantly better on postural stability measurements and had fewer falls
  - Rating:  safe, low risk, may be effective

CAM in PD

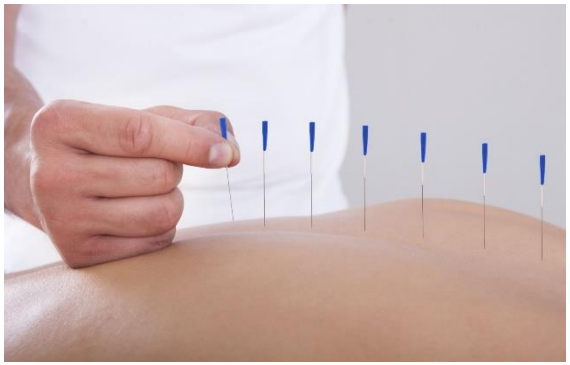
- Yoga
  - Handful of small studies have shown benefit in motor scores, balance and mood in PD
  - Many of the control groups did no intervention (no exercise) so difficult to say whether yoga specifically improved PD symptoms or if the effect was due to physical exercise in general
  - Rating:

CAM in PD

- Resistance training (strength training):
  - Studies show improved strength in PD, may improve gait and motor scores (mixed results)
- Endurance training (treadmill, elliptical, stationary bike):
  - Improves cardio-respiratory fitness in PD
  - May improve balance, gait (mixed results)
- Other intensive training exercises (Boxing, mixed strength/endurance training)
  - May improve strength, balance, gait and motor scores in PD (mixed results)

- Rating: 

CAM in PD



- Acupuncture
  - Long-standing part of traditional Chinese medicine
  - Involves placing tiny needles in strategic parts of the body to balance flow of energy
  - Several studies done in PD with mixed results (some showing benefit others not showing benefit)
  - 3 randomized controlled/sham studies showed no benefit over placebo
  - While not harmful, no good evidence at this time to do acupuncture specifically for PD

  - Rating:

Nutrition in PD

- Are there any foods I should avoid or I should eat more of to help my Parkinson's symptoms?
- There is no one superfood in Parkinson's

Nutrition in PD

- Protein sensitivity
  - Consuming protein rich foods at same time as carbidopa/levodopa (Sinemet) can block absorption of medication in gut in some patients
  - Try taking Sinemet 30 minutes before or 60 minutes after eating if possible
  - This DOES NOT mean you should not consume protein
- Iron supplements
  - Can also block absorption of levodopa so take at least an hour before or after taking levodopa

Nutrition in PD

- Mediterranean Diet?
  - Consists of high intake of vegetables, fruits, unsaturated fatty acids ("good" fats), legumes, whole grains, fish and moderate consumption of wine with limited dairy, meat and poultry.
  - Several studies looking at this in PD

Nutrition in PD

Mov Disord. 2019 Jan;34(1):48-57. doi: 10.1002/mds.27489. Epub 2018 Oct 10.

Mediterranean diet adherence is related to reduced probability of prodromal Parkinson's disease.

Maraki MI[1], Yannakoulia M[1], Stamelou M[2,3], Stefanis L[3,4], Xiromerisiou G[5], Kosmidis MH[6], Dardiotis E[5], Hadjigeorgiou GM[5], Sakka P[7], Anastasiou CA[1,3], Simopoulou E[5], Scarmeas N[3,8].

Author information

Abstract

BACKGROUND: The International Parkinson and Movement Disorder Society recently introduced a methodology for probability score calculation for prodromal PD.

OBJECTIVES: To assess the probability of prodromal PD in an older population and investigate its possible association with Mediterranean diet adherence.

METHODS: Data from a population-based cohort study of older adults (HEllenic Longitudinal Investigation of Aging and Diet) in Greece were used. Probability of prodromal PD was calculated according to International Parkinson and Movement Disorder Society research criteria. A detailed food frequency questionnaire was used to evaluate dietary intake and calculate Mediterranean diet adherence score, ranging from 0 to 55, with higher scores indicating higher adherence.

RESULTS: Median probability of prodromal PD was 1.9%, ranging from 0.2 to 96.7% in 1,731 PD-free individuals aged ≥ 65 (41% male). Lower probability for prodromal PD ($P < 0.001$) in the higher Mediterranean diet adherence groups was noted, driven mostly by nonmotor markers of prodromal PD, depression, constipation, urinary dysfunction, and daytime somnolence. Each unit increase in Mediterranean diet score was associated with a 2% decreased probability for prodromal PD ($P < 0.001$). Compared to participants in the lowest quartile of Mediterranean diet adherence, those in the highest quartile were associated with a ~21% lower probability for prodromal PD.

CONCLUSIONS: Adherence to the Mediterranean diet is associated with lower probability of prodromal PD in older people. Further studies are needed to elucidate the potential causality of this association, potential relation of the Mediterranean diet to delayed onset or lower incidence of PD, as well as the underlying neurobiological mechanisms. © 2018 International Parkinson and Movement Disorder Society.

KEYWORDS: Mediterranean; elderly; neurodegeneration; nutrition; prodromal

Nutrition in PD

- Two other studies in US showed decreased odds of PD in those who adhered to Mediterranean diet
- Limitations?
  - Possible diet recall bias
    - Early cognitive changes
  - Prodromal PD symptoms playing a role in diet?
    - Lack of smell or depression/anxiety playing a role in a less healthy diet
  - Association doesn’t always imply causation

Nutrition in PD

- Mediterranean diet?
  - Safe
  - Numerous studies showing decreased risk of heart disease and stroke
  - Possibly protective against neurodegenerative diseases
  - Rating: 

Nutrition in PD

- Fluids Matter!
  - Drink plenty of fluid which helps prevent fluctuations in blood pressure and constipation
  - Water is best
  - Aim for around 60 oz per day

Thank you!

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Building Your Exercise Toolkit

Lindsey Hershberger, DPT
PWR!® Certified
NeuroRehab and Balance Center
Lindsey.Hershberger@ketteringhealth.org

Symptom: Stooped Posture

Why is having good posture important?

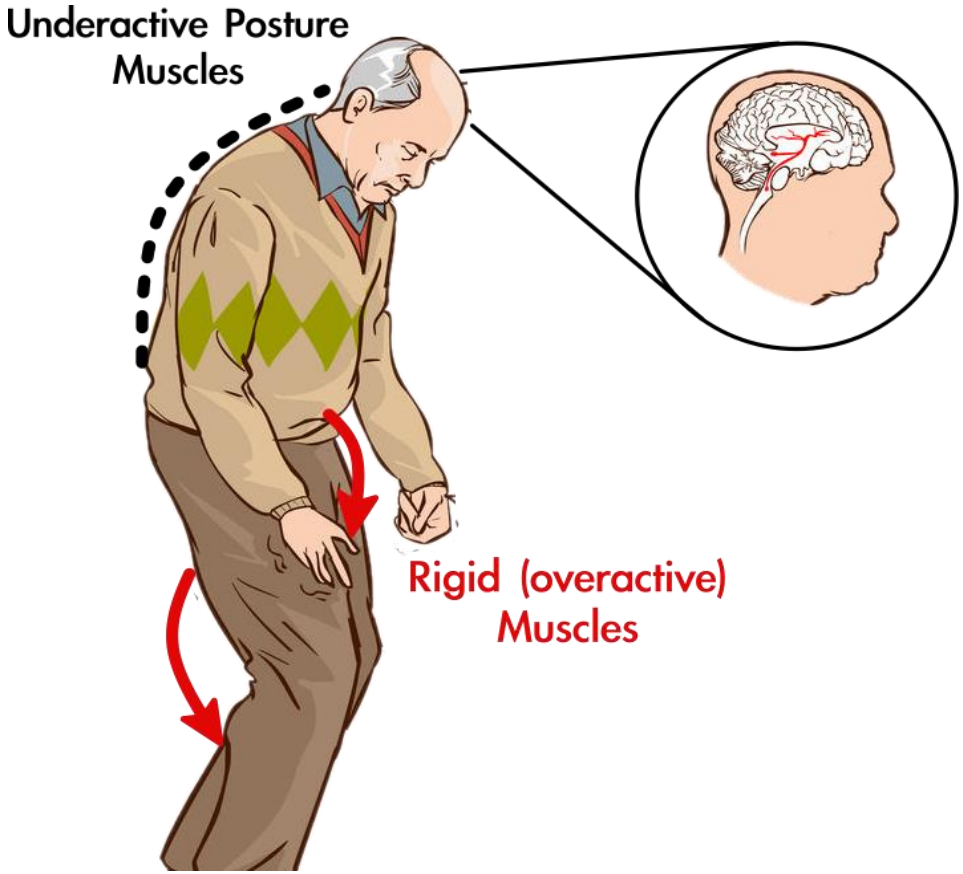
1. Falls
2. Function
3. Freezing
4. Walking
5. Pain

Considerations

Goal: Stretch the short/overactive muscles on the front side of your body and strengthen the long/underactive muscles on the back side of your body.

Postural muscles are endurance muscles that need to stay "on" for long periods of time throughout the day. When exercising, think sustained, functional positions.

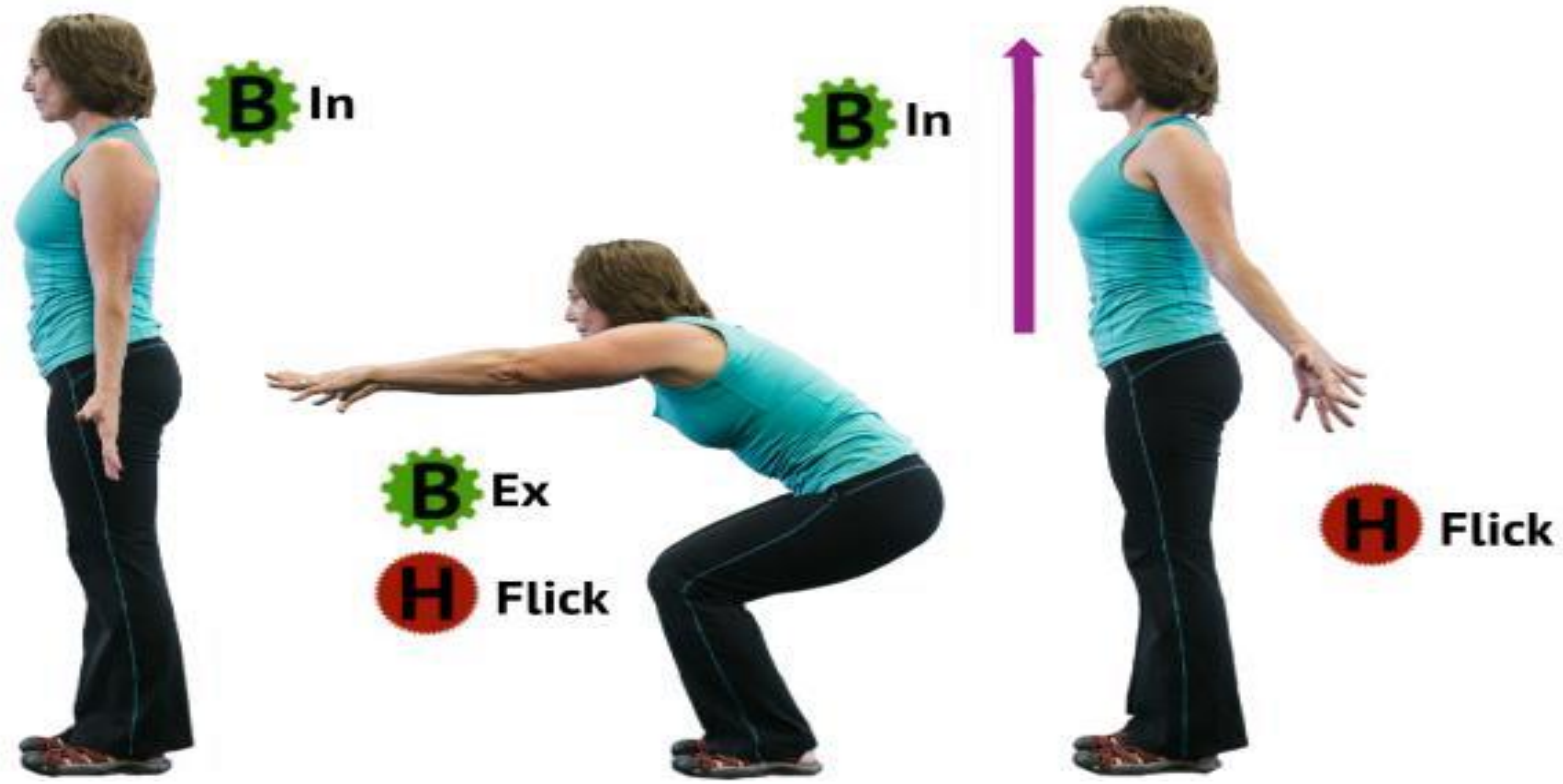
PD tends to make movements small. Train your brain to move BIG.



PWR!® Up: Sitting

For video reference, go to YouTube.com and search “PWR! Moves Sitting”

PWR!® Up in Standing



For video reference, go to YouTube.com and search “PWR! Moves Standing”

Progression Ideas

- Practice in different positions (search PWR! Moves on YouTube for video reference)
- Add resistance band or weights
- Add hand flicks
- Add breath work
- PWR! Up on to tip toes or add jumping
- Add ball toss or ball bounce to self or partner
- Stand on foam, grass, or graded surface to challenge balance
- Add cognitive challenge by tracking reps in a way other than traditional counting
  - Alternating numbers and letters (1-A-2-B-3-C-4-D)
  - Naming the months of the year forward or backwards
  - Category naming (i.e. name fruits in down position, name vegetables in the up position)

Wellness ~~in~~ and Parkinson's Disease

Patricia Colapietro, MD
Assistant Professor of Neurology
University of Cincinnati
Gardner Neuroscience Institute

Welcome

Integrative Neurology

~~DISEASE focused model~~

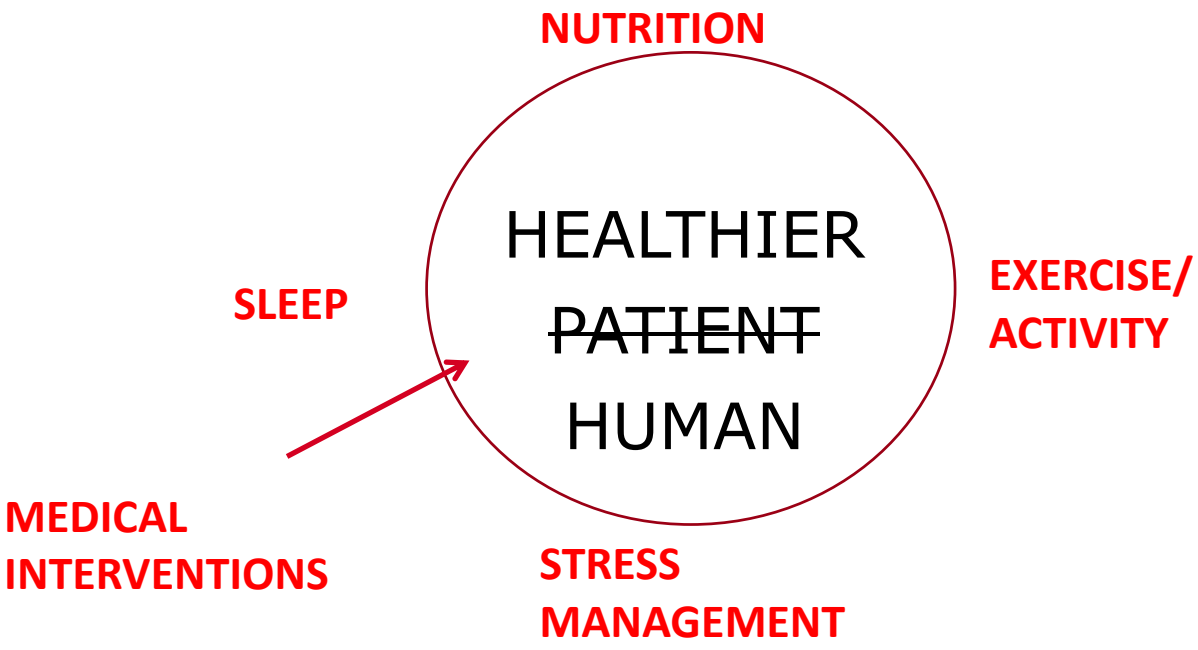
HEALTH promotion model

~~PARKINSON'S PATIENT~~

HUMAN with PD

Integrative Neurology

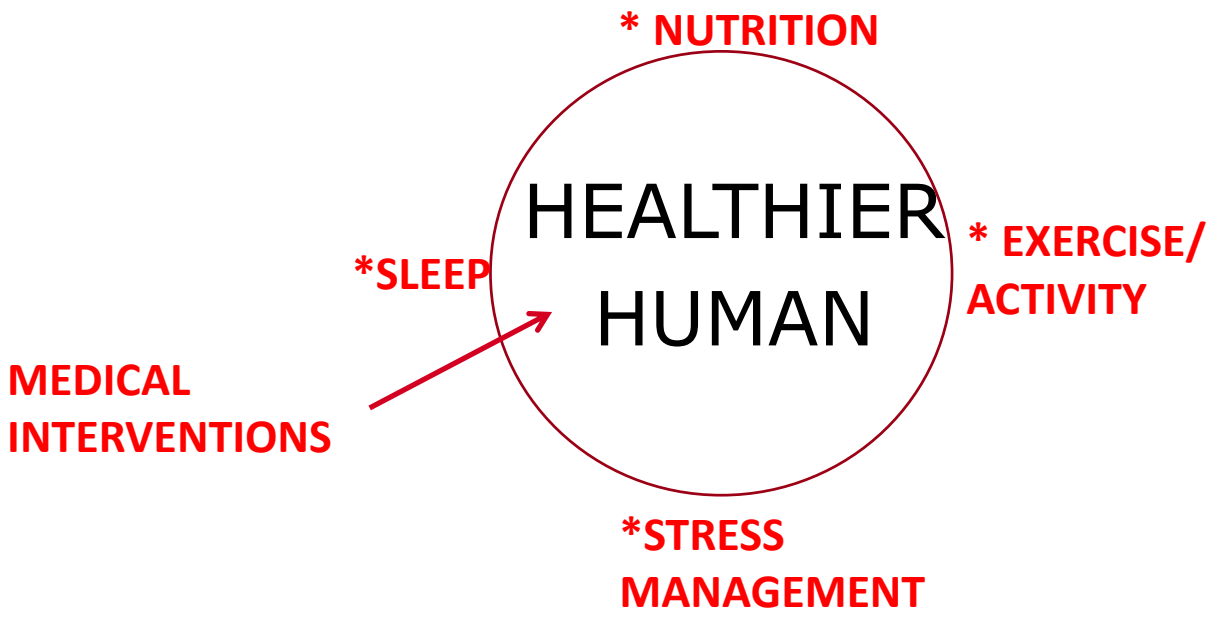
American Academy of Neurology annual meeting 2019



Integrative Neurology

MEDITATION

- RELAXATION
- MINDFULLNESS *



Mindfulness Exercise

Integrative Neurology

Healthier Human

Healthier Family/Friends/Care Providers

Healthier Society

Thank You

Patricia Colapietro, MD

UC Neurology

Building Your Exercise Toolkit

Luke Barrett
NASM Certified, Rock Steady Boxing Coach
Owner, GeoFit

Symptom:
Decreased Weight Shift

Why is weight shift important?

- Bed mobility
- Getting in or out of a chair
- Walking
- Turning
- Prevent Falls

Weight Shift

- The inability to rock or weight shift contributes to freezing and falls.
- Rocking is a strategy that can trigger a step when hesitant or feeling stuck.
- Rocking reinforces a wider base of support during walking and turns which decreases falls risk.

GOAL:

Improve weight shift in all positions for increased independence and decreased risk of falls

PWR! Rock in Sitting

PWR! Rock in Standing

Functional Activities that Correlate to PWR! Rock

- Reaching under the bed
- Reaching to turn the nightstand light on/off
- Gardening/Yardwork
- Getting up from the floor
- Picking up an object from the ground
- Breaking a freeze
- Dancing!

Progression Ideas

Progression Ideas

- Practice in different positions (search PWR! Moves on YouTube for video reference)
- Add resistance band or weights
- Add PWR!Moves Breath, Hand, Voice and/or Eye Boosts
- PWR! Rock and reach for objects on higher and lower surfaces
- PWR! Rock and reach on balance disks, BOSU or on ½ foam rollers
- Add cognitive and motor challenges with dual task activities:
  - Rock and reach to the right and say a color, rock and reach to the left and name a State.
  - Counting backwards by 7's as you rock forward to touch the target in front and rock back to hit the target behind
  - Bounce a tennis ball or basketball while rocking side to side

Parkinson's and the Wine Store

Marty Piazza

Background

- Co-owner of wine retailer Piazza Discepoli
- I am 67 years old
- Diagnosed with Parkinson's 4 years ago
- Born & raised in Cincinnati, Ohio
- Spent 10 years in New York city, working on Wall Street
- Returned to Cincinnati in 1988
- Worked for Key Bank until 2000

The Wine Business

- While working at Key also started a retail wine business with my good friend, Guy Discepoli
- For 12 years Guy got the business going, while my career advanced at Key
- In 2000 Key restructuring gave opportunity to jump full time into wine business

Logo

Exterior Madeira

Interior Madeira

Nino the Wine Dog

Parkinson's Enters the Scene

- My Mother was diagnosed with Parkinson's Disease in 1982
- One reason why we moved back to Cincinnati
- An introverted artist who painted prolifically
- Lived for 20 years with the disease
- "Not hereditary"


Elaine Piazza

My Turn

- Jump to 2015– 4 Wine Stores & Wine Bar
- Cold Walk Home - Despair
- "You are not going to have your mother's Parkinson's Disease!"
- Rebuilding begins. "I can do that!"
- Decided not to hide it
- Vultures circling the store
- Restructure our business

Symptom Managers

- Exercise
- Don’t waste good days
- Wait 20-30 minutes before worrying
- Take slow, deep breaths
- Meds on empty stomach, same time
- Clinical Trials
- Creative Visualization

Building Your Exercise Toolkit

Cindy Kester, BS/PT

LSVT Big® Certified

University of Cincinnati Gardner Neuroscience Institute

Symptoms:

Stiffness and rigidity of the trunk

- Why is it important to twist well?
- Twisting movements and exercise help to combat the stiffness and rigidity
- Better range of motion within the ribs and spine will lead to better movement in the hips and shoulders

Rotation in Daily Activity

- Opening doors
- Getting out of bed
- Driving
- Household chores: cooking, vacuuming, sweeping, raking, loading dishwasher
- Athletics: golf, tennis, yoga, tai chi, swimming, walking

Toolkit for Rotations: Sitting

Side to Side

Progressions: Hand flicks, high to low reaches, target, counting reps

Important Pointers: feel comfortable on seat. Breathing into lower ribs and watch for shoulder shrugging, but reach BIG!

Toolkit for Rotations: Standing

Sideways Rock and Reach

Progressions: Hand flicks, punching, changing speeds, high and low targets

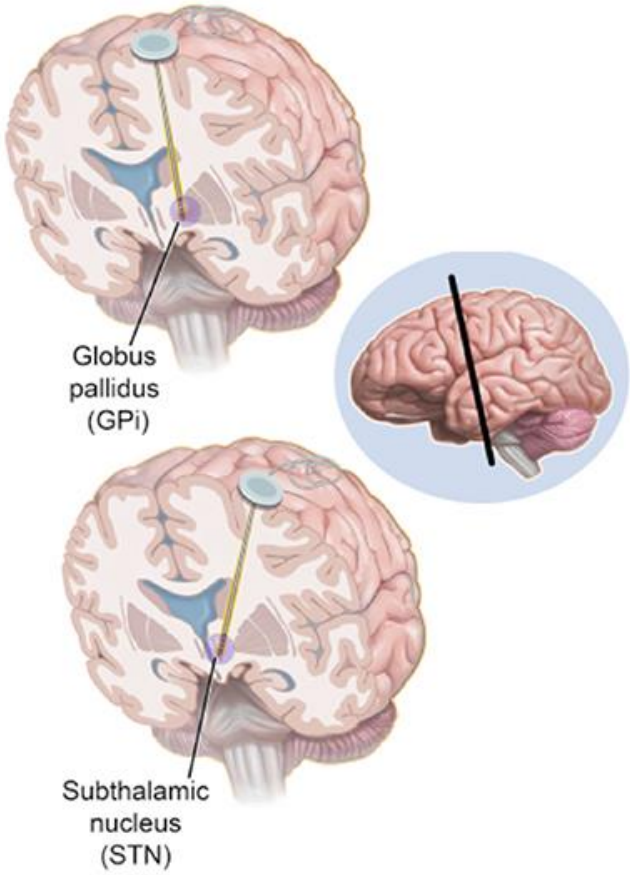
Important pointers: Aim for full range of motion and your best posture

Probing the Future: A New Era of Deep Brain Stimulation

Juan Torres-Reveron, MD/PhD
Director, Functional and Epilepsy Surgery
Department of Neurosurgery

Deep Brain Stimulation (DBS)

- Surgery approved for the treatment of Parkinson's disease, essential tremor, dystonia and epilepsy
- Involves the placement of electrodes deep in the brain connected to a generator in the chest
- FDA approved since 1997
- More than 100,000 surgeries around the world



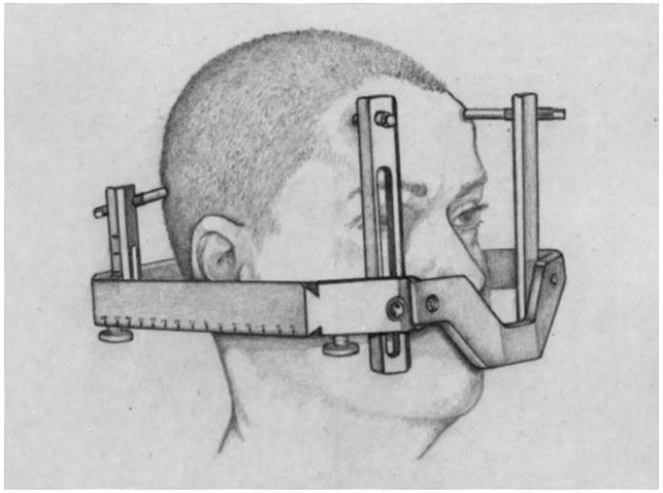
Who is a candidate for DBS?

- Classic Parkinson's disease for at least 4 years
- Responsive to dopamine medications (levodopa - Sinemet)
- No psychological contraindications (dementia, schizophrenia…)
- No major medical diseases preventing surgery (active cancer, severe lung or cardiac problems…)
- Patients suffering from undesirable side effects from medication (dyskinesia, prominent on/off times, sedation…)

How does UC evaluate a good DBS candidate?

- Referral to our center by primary doctor or neurologist
- Evaluation using the Uniform Parkinson's Disease Rating Scale (UPDRS) with and without medication
- Neuropsychological testing
- MRI of the brain, sometimes DaT scan
- Presentation at UC DBS conference to obtain opinion of the group

How is DBS performed?



Frame placement

CT scan

Placement of electrodes

Overnight stay in hospital

1 week

Placement of generator

2 weeks

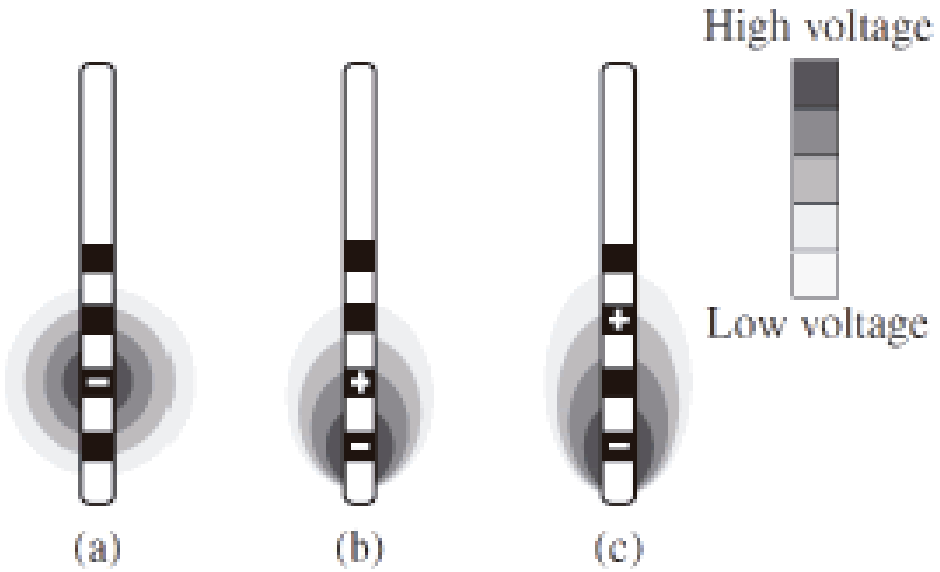
Programming of generator

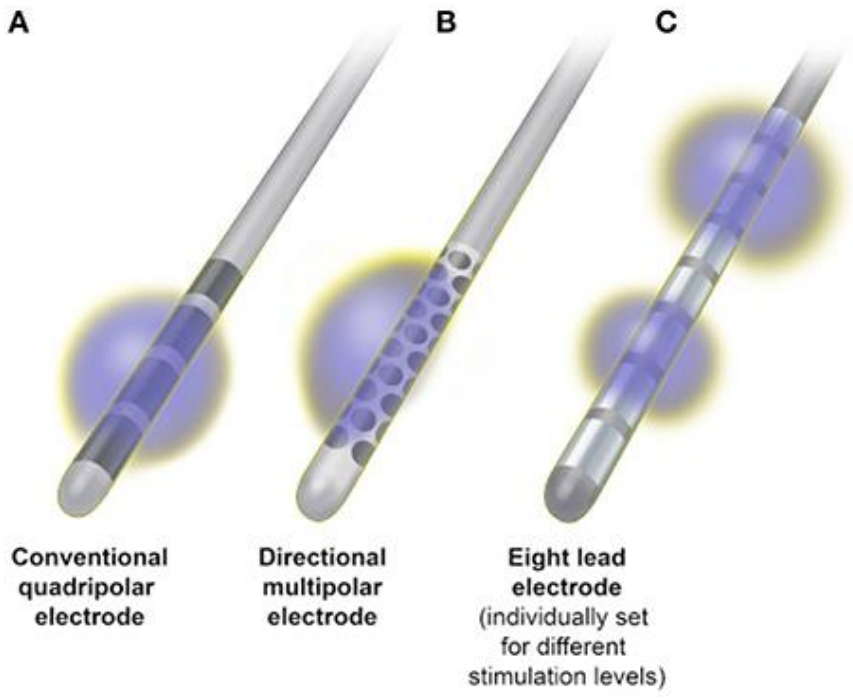
Before the DBS era…

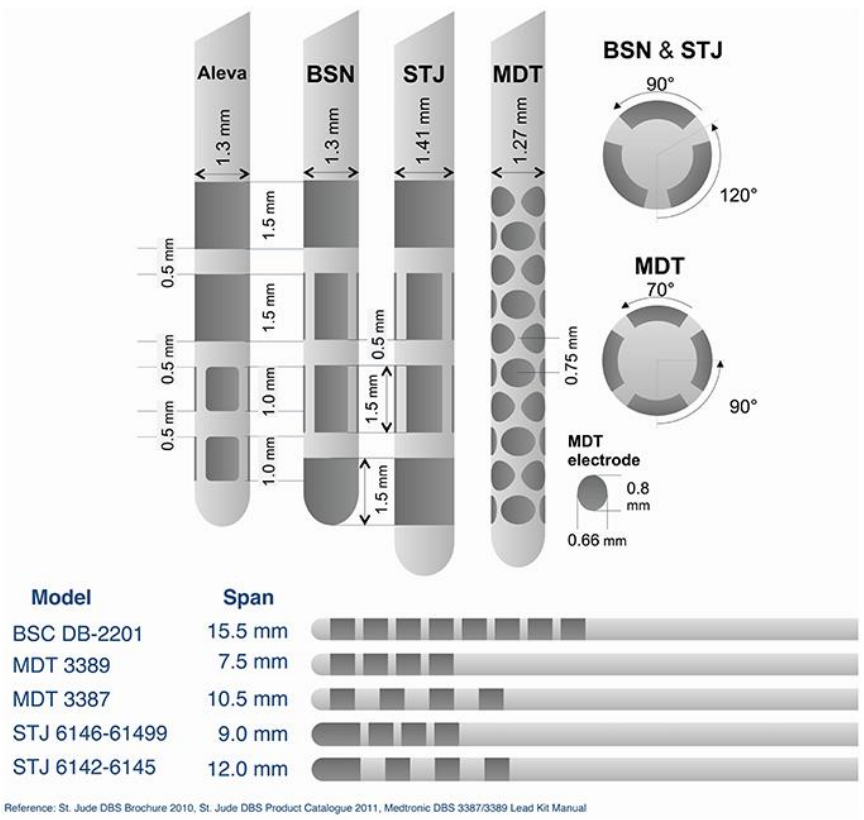
- **Radiofrequency ablation**
  - Probe placed in the thalamus or globus pallidus
  - Radiofrequency applied through probe to cause lesion in the brain
  - Advantages
    - Single-session surgery
    - No programming needed
  - Disadvantages
    - No modulation over time
    - No way to eliminate side effects

Basic DBS Electrode

- Four round contacts at the end
- Distance between contacts varies
- Voltage can be applied to a single contact or multiple contacts
- Generates a cloud of electrons that affect brain cells
- Can increase or decrease voltage to desired effect



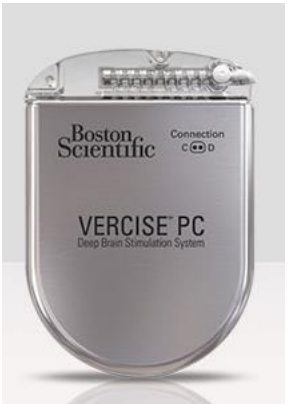




Evolution of DBS electrodes

Evolution of DBS generators

- Rechargeable or primary cell
- Voltage or current adjustments
- Capacity for independent contact control



Improvement in DBS Systems

- **Old Systems**
  - Non-MRI compatible
  - Limited options for stimulation pattern
  - Frequency limited
  - Short battery life
- **New Systems**
  - Rechargeable or primary cell
  - Some systems fully MRI compatible
  - Independent control of multiple contacts
  - Higher stimulation frequencies available
  - Longer battery life

Future of DBS

- Systems that intermittently turn on/off based on the tremor
- Generators that can record brain activity to help with programming of the device
- Automatic programming based on brain signals
- Asleep procedures (with or without MRI guidance)

UC Health IN SCIENCE LIVES HOPE.

Questions?

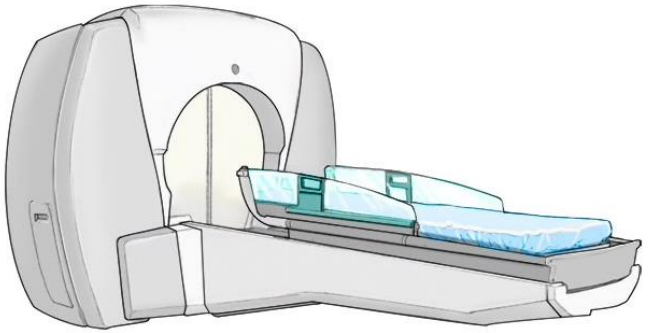
Referrals:

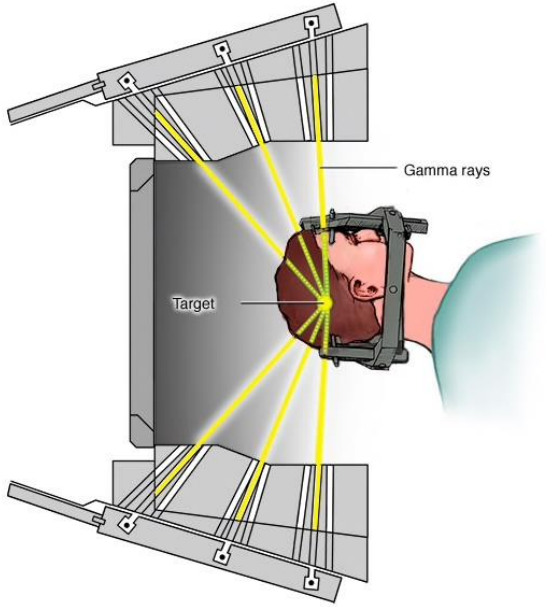
Phone: 513-475-8990

Fax: 513-475-8559

Gamma knife radiosurgery

- Focused radiation to cause a lesion
- Used to treat tumors as well
- Single lesion
- Requires the placement of a frame
- No neuromodulation
- **No surgical incision**

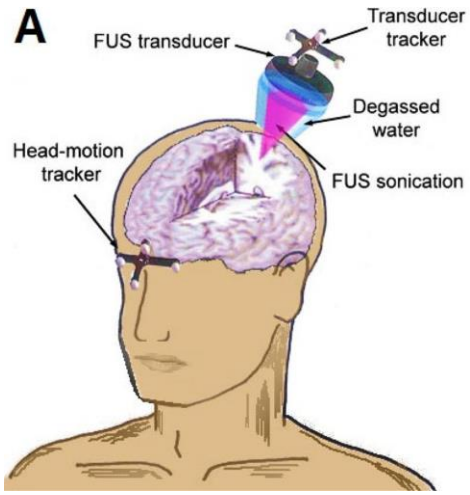


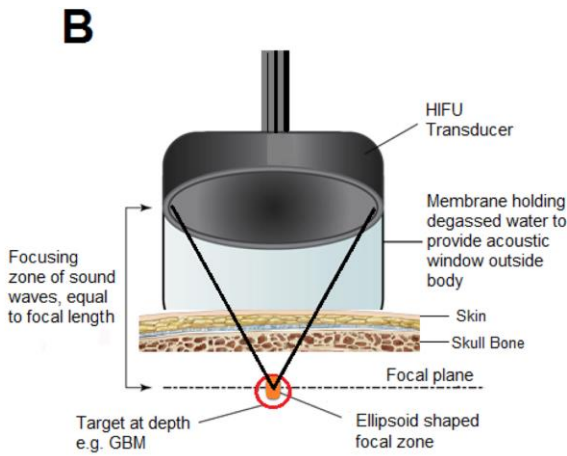


Gamma Knife unit and radiation delivery

High frequency focused ultrasound (HIFU)

- Invented in the 1950s
- Performed in MRI to monitor temperature
- Limited availability throughout the US
- Single lesion
- No neuromodulation
- Tremor control is limited
- **No surgical incision needed**





Do we want to discuss HIFU and gamma knife when they are really for essential tremor and not PD? Consider deleting these. Plus, we don't offer them. Maybe we could give more information on DBS patient selection, the team approach, results, complications, side effects?

sunflower REV IT UP for parkinson's

WALK RUN RIDE LEARN

Sunflower Rev It Up for Parkinson's Walk/Ride/Run

Sunday, September 8, 2019

Sawyer Point, Cincinnati

3K walk 'n roll

5K walk/run

Family bike ride

30K & 60K bike

New for 2019!-Register as a virtual participant!

Support Sunflower from the comfort of your couch.

For more information, visit SunflowerRev.org or call (513) 558-6903

2019 Victory Award

Carole and Dave Ebner

The Cincinnati Cohort Biomarker Program—Blazing New Trails

Alberto J. Espay, MD, MSc, FAAN

Professor of Neurology

Director and Endowed Chair

James J. and Joan A. Gardner Family Center

for Parkinson's Disease and Movement Disorders

University of Cincinnati

Disease-modifying trials: consequence of one-size-fits-all

Completed Phase 3 trials

Vitamin E
Antioxidant

GPI-1485
Neuroimmunophilin

Riluzole
Glutamate antagonist

TCH346
Propargylamine

CEP-1347
Anti-apoptotic

GDNF
Intraputaminal neurotrophic factor

Co Q10
Mitochondrial enhancer

Mitoquinone
Mitochondrial enhancer

Pramipexole
Dopamine agonist

Cogane
Modulates GDNF & BDNF (PYM50028)

Creatine
Mitochondrial modulator

Pioglitazone
PPAR γ agonist; anti-inflammatory

Rasagiline
MAO-B inhibitor

Success in Phase 3 trials: 0/17

Glutathione
Antioxidant

…in the pipeline

Phase 3

Isradipine
Calcium-channel blocker

Inosine
Calcium-channel blocker

Phase 2

Exenatide (-like)
GLP1 agonist

Deferiprone
Iron trapping

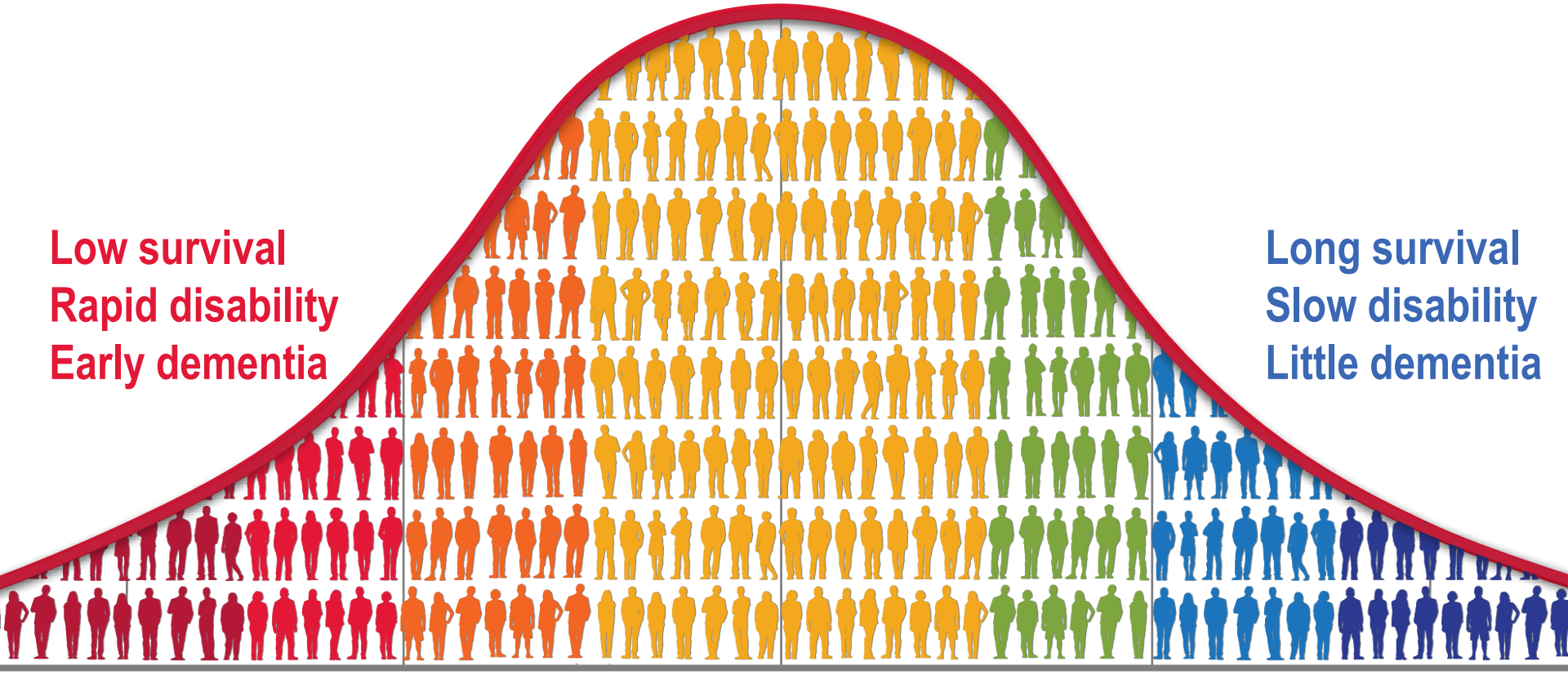
Ambroxol
Increases lysosomal function

AFFiRiS, Prothena, Biogen
α-synuclein immuno-Rx

Genzyme, LTI Rx
GCase path mod

? Denali Rx
LRRK2 inhibitor

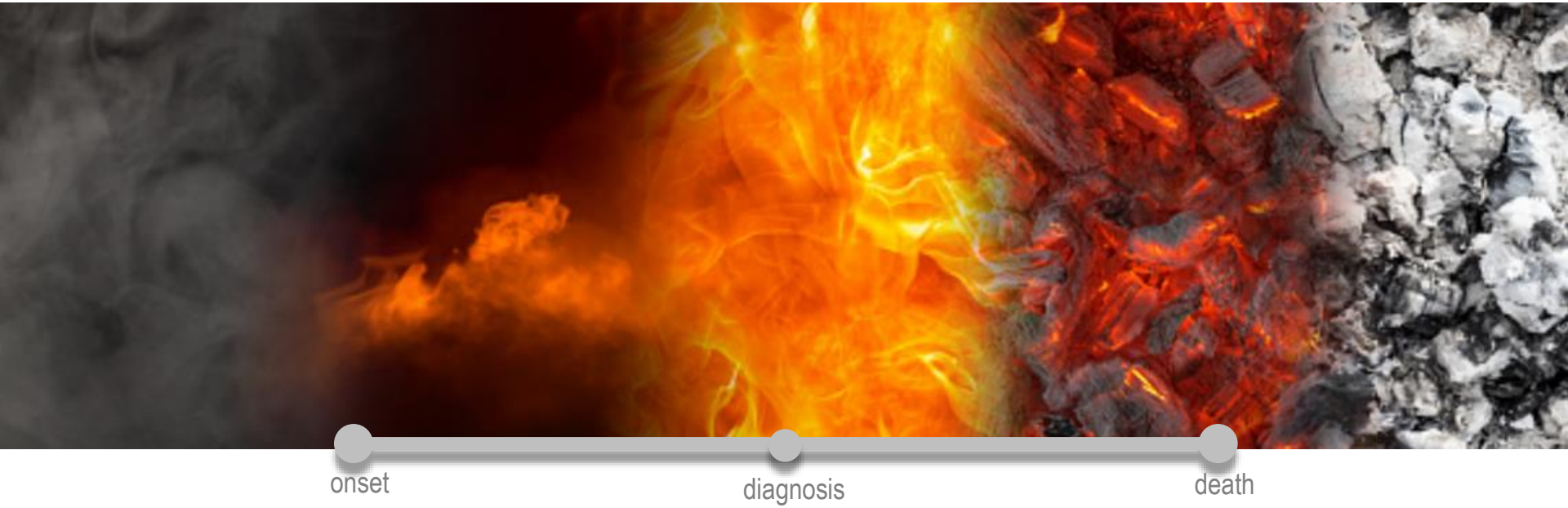
Why is our definition of "PD" problematic?



All meet clinical criteria for PD

Our reassurance: "PD is a heterogeneous disease"

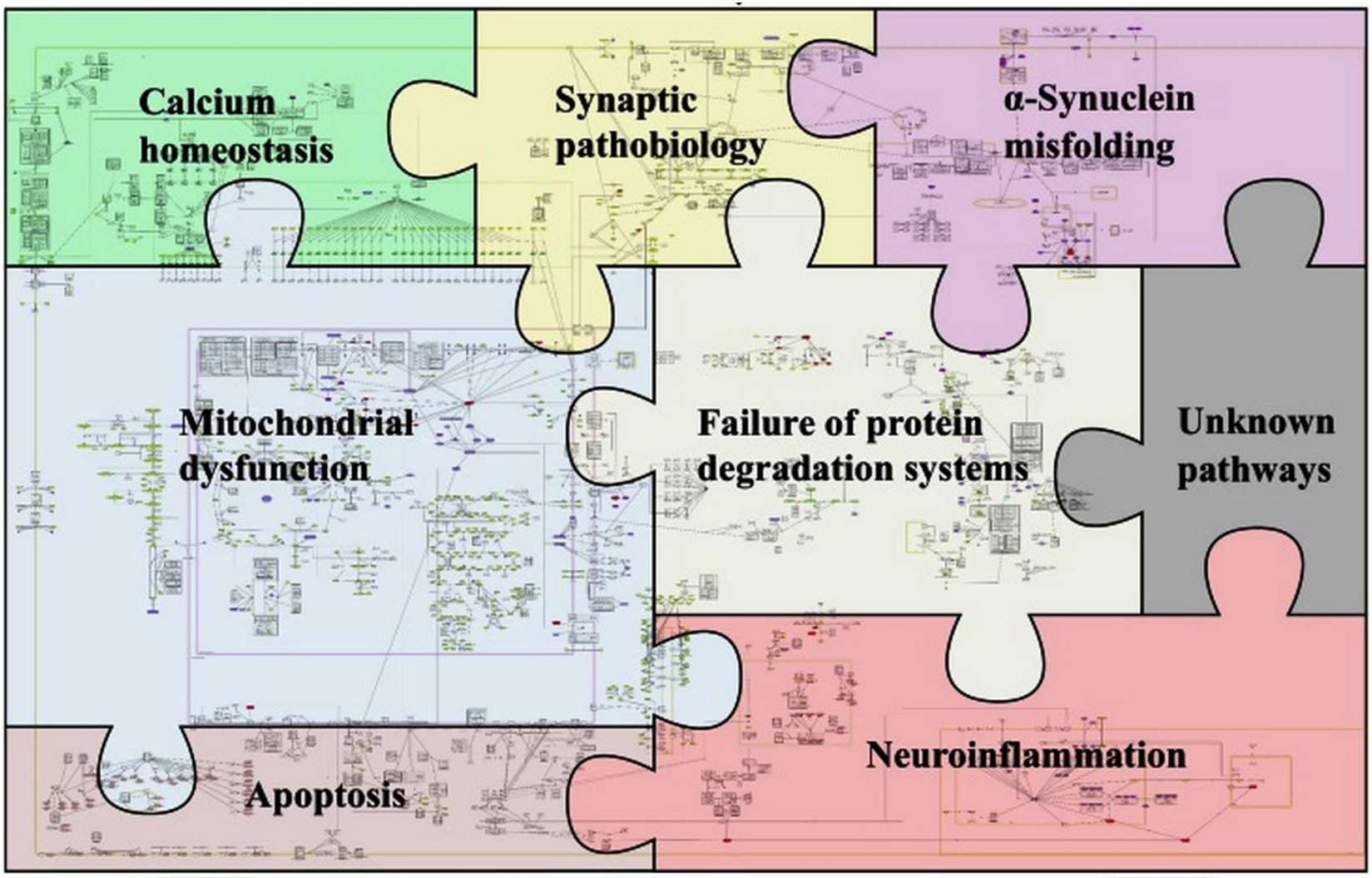
Parkinson's = Forensic research



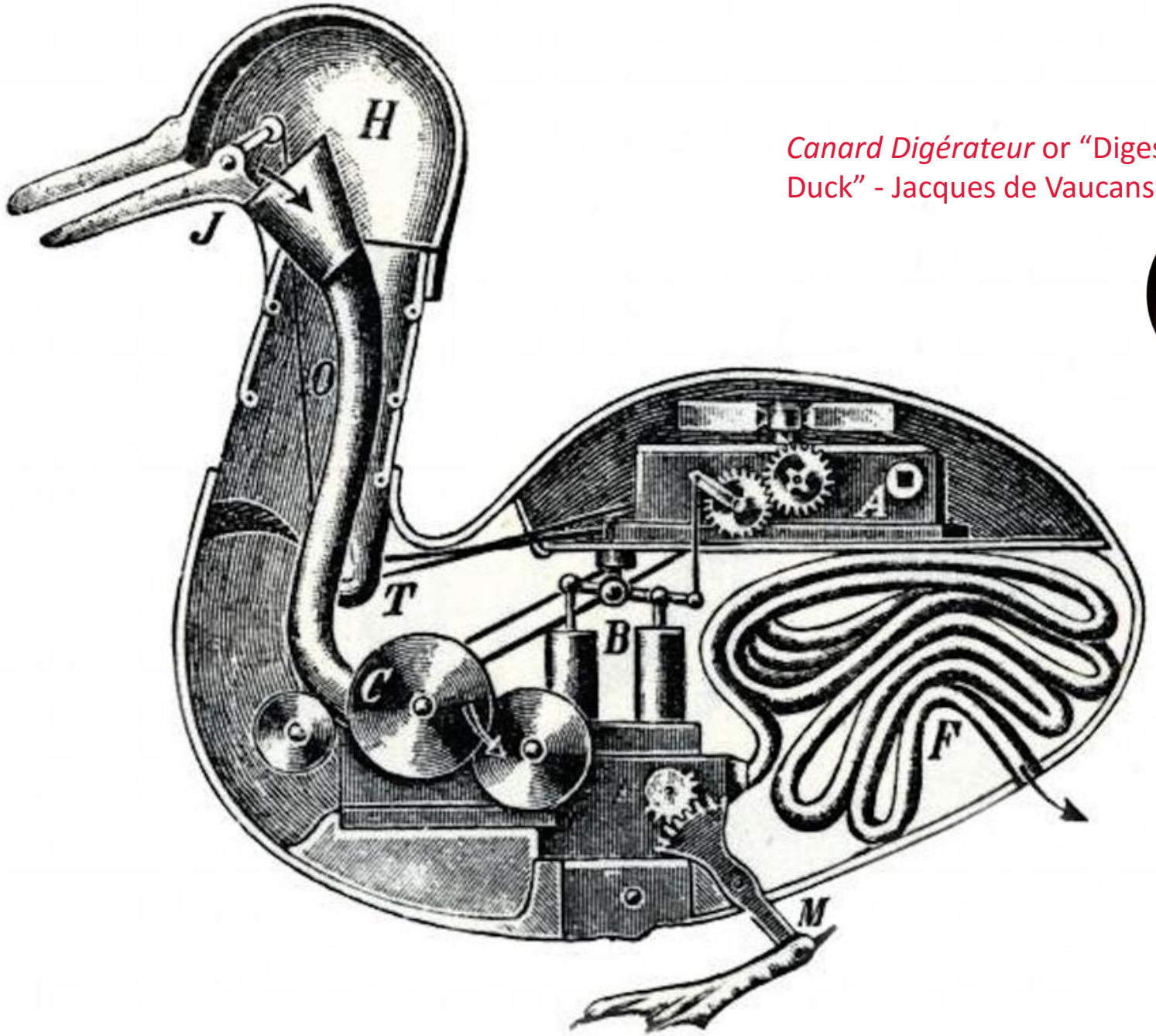
We scavenge clues about the source of a fire from its "smoke" (e.g., neuroimaging, CSF), its effects in remote neighborhoods (e.g., skin biopsy) – or from the ashes left after the fire (autopsy).


onset
diagnosis
death
Lewy body

Biological systems involved in Parkinson's



Fujita KA, Ostaszewski M, Matsuoka Y, Ghosh S, Glaab E, Trefois C, et al. Integrating pathways of parkinson's disease in a molecular interaction map. *Mol. Neurobiol.* 2014;49:88-102



Canard Digérateur or “Digesting Duck” - Jacques de Vaucanson

Dementia

REM sleep behavior disorder

Canard Digérateur or "Digesting Duck" - Jacques de Vaucanson

Alpha synuclein accumulation

Hypophonia

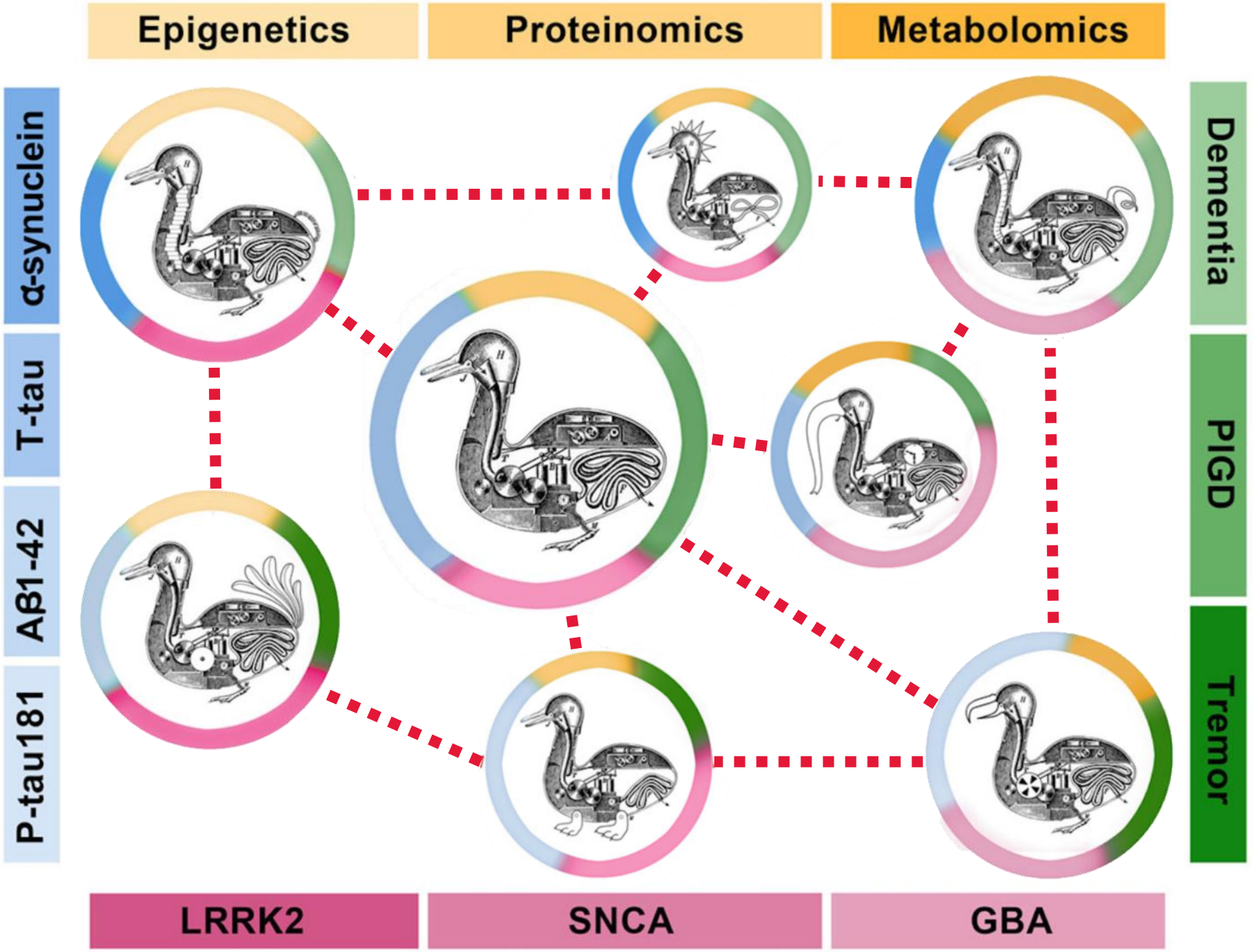
Axial dystonia

Cardiac sympathetic denervation

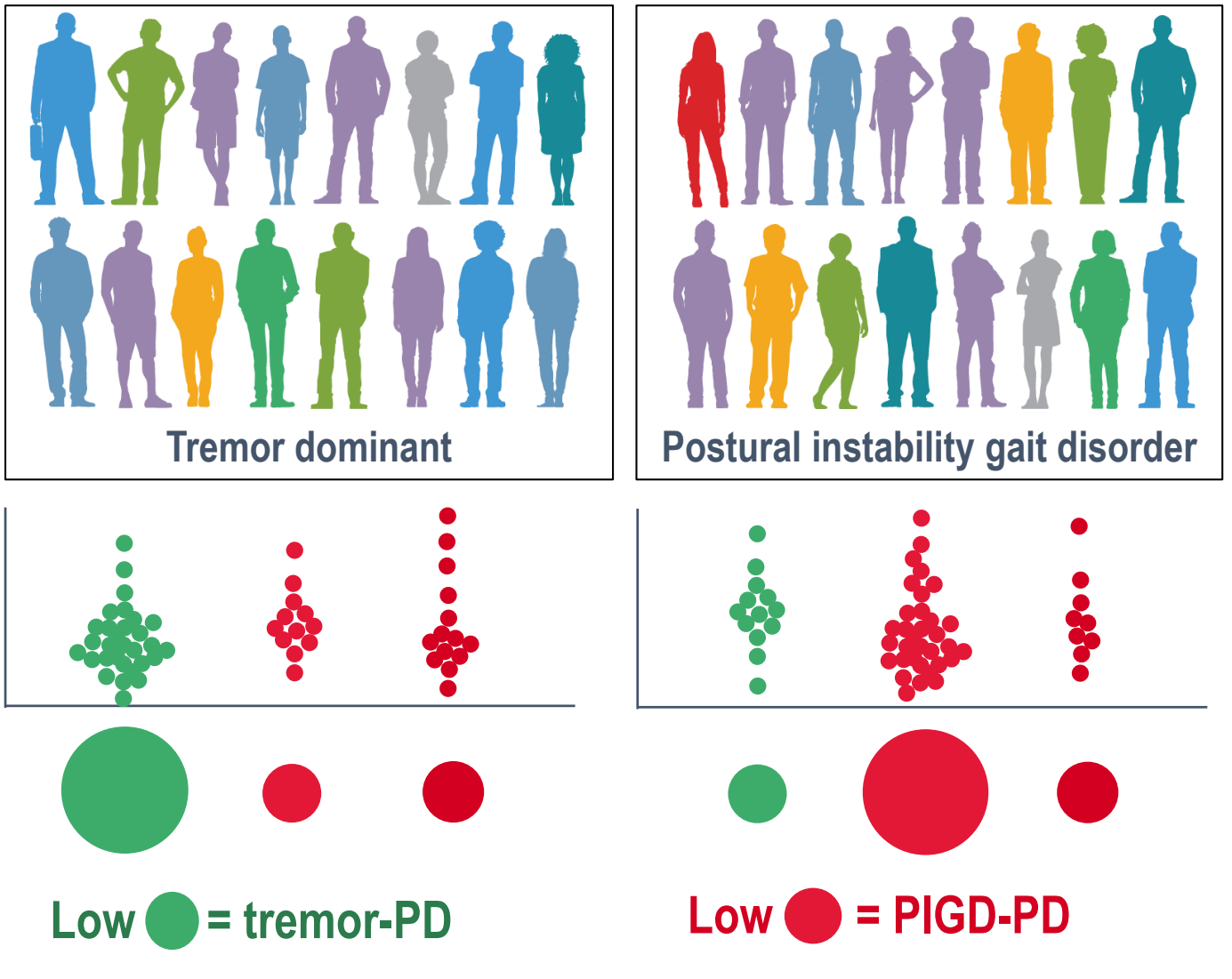
Constipation

Tremor

Gait freezing


Epigenetics
Proteinomics
Metabolomics
α-synuclein
T-tau
Aβ1-42
P-tau181
Dementia
PIGD
Tremor
LRRK2
SNCA
GBA

Searching for biomarkers

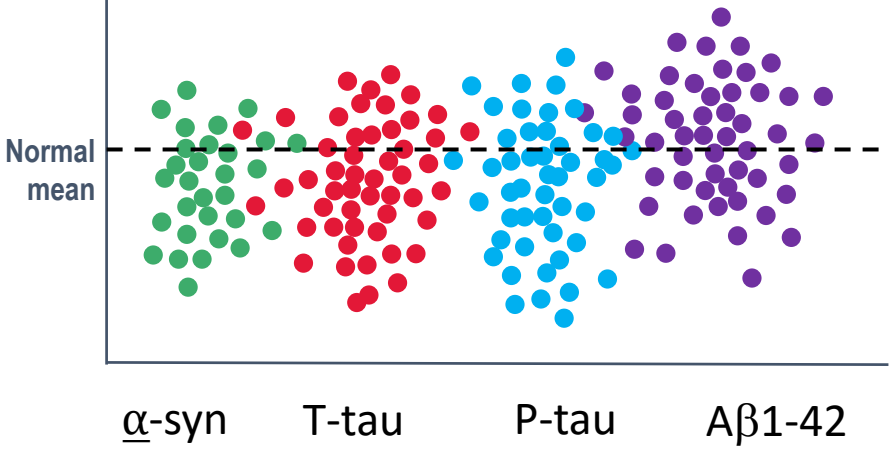


Espay AJ, *et al*. Mov Disord. 2017 Mar;32(3):319-324

Little congruence across cohorts

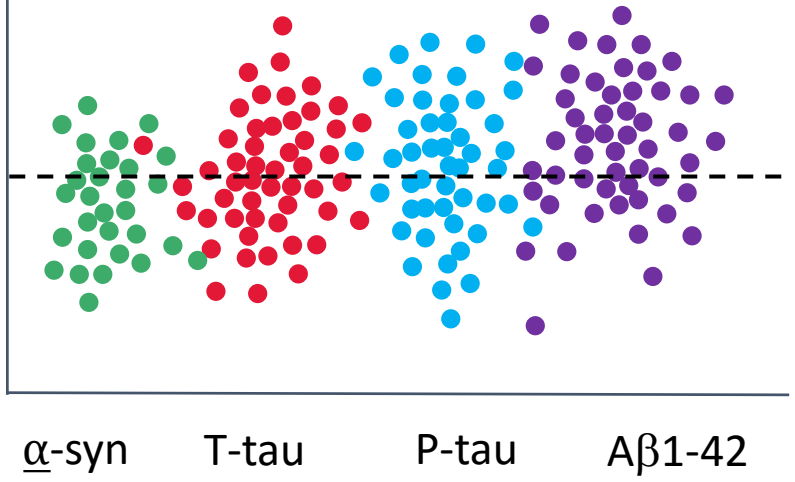
PPMI study (n = 412)

Low: α-syn, **T-tau, P-tau**
Normal: A-β1-42



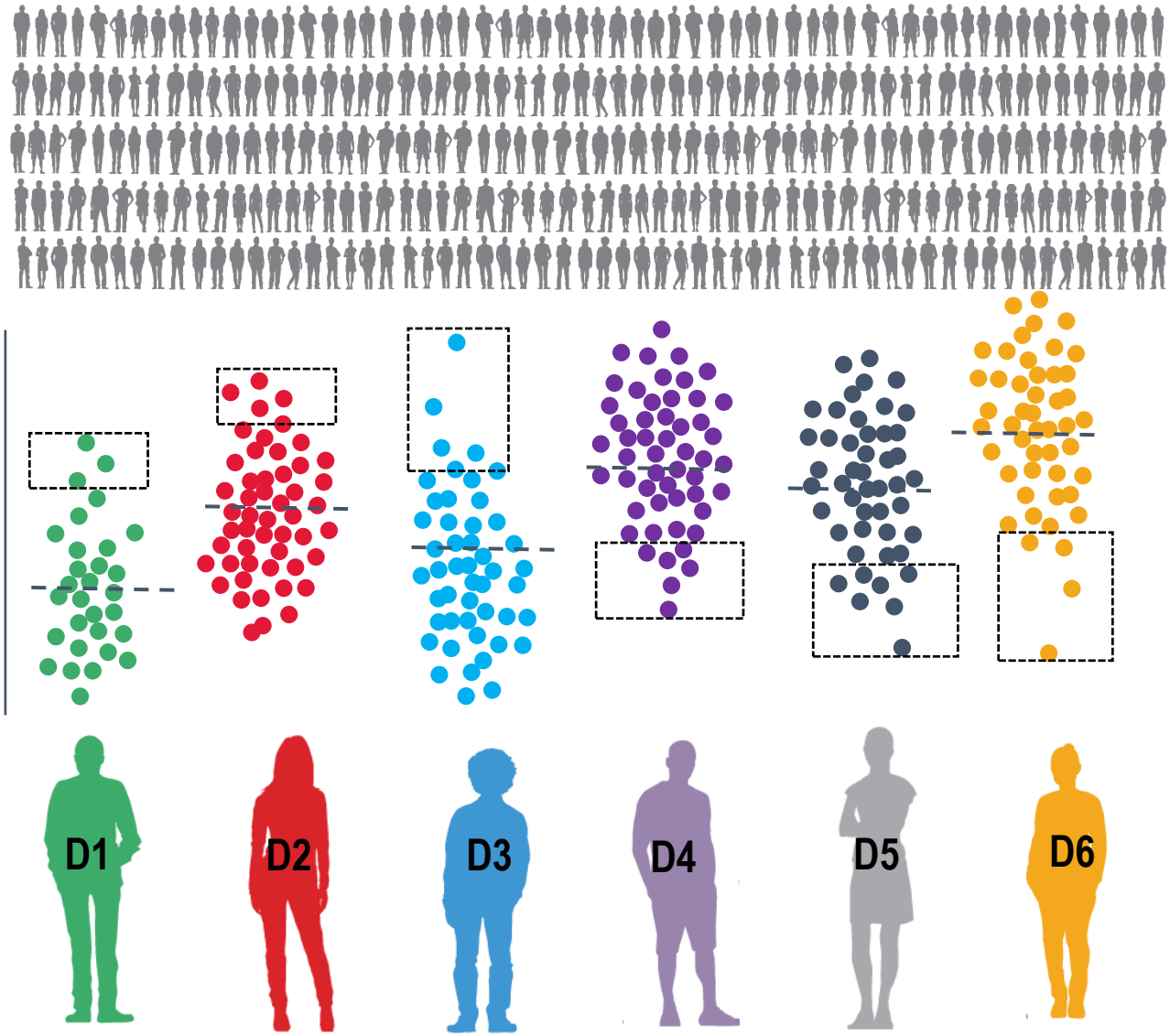
DeNoPa study (n = 123)

Low: α-syn
Normal: **T-tau, P-tau,** A-β1-42



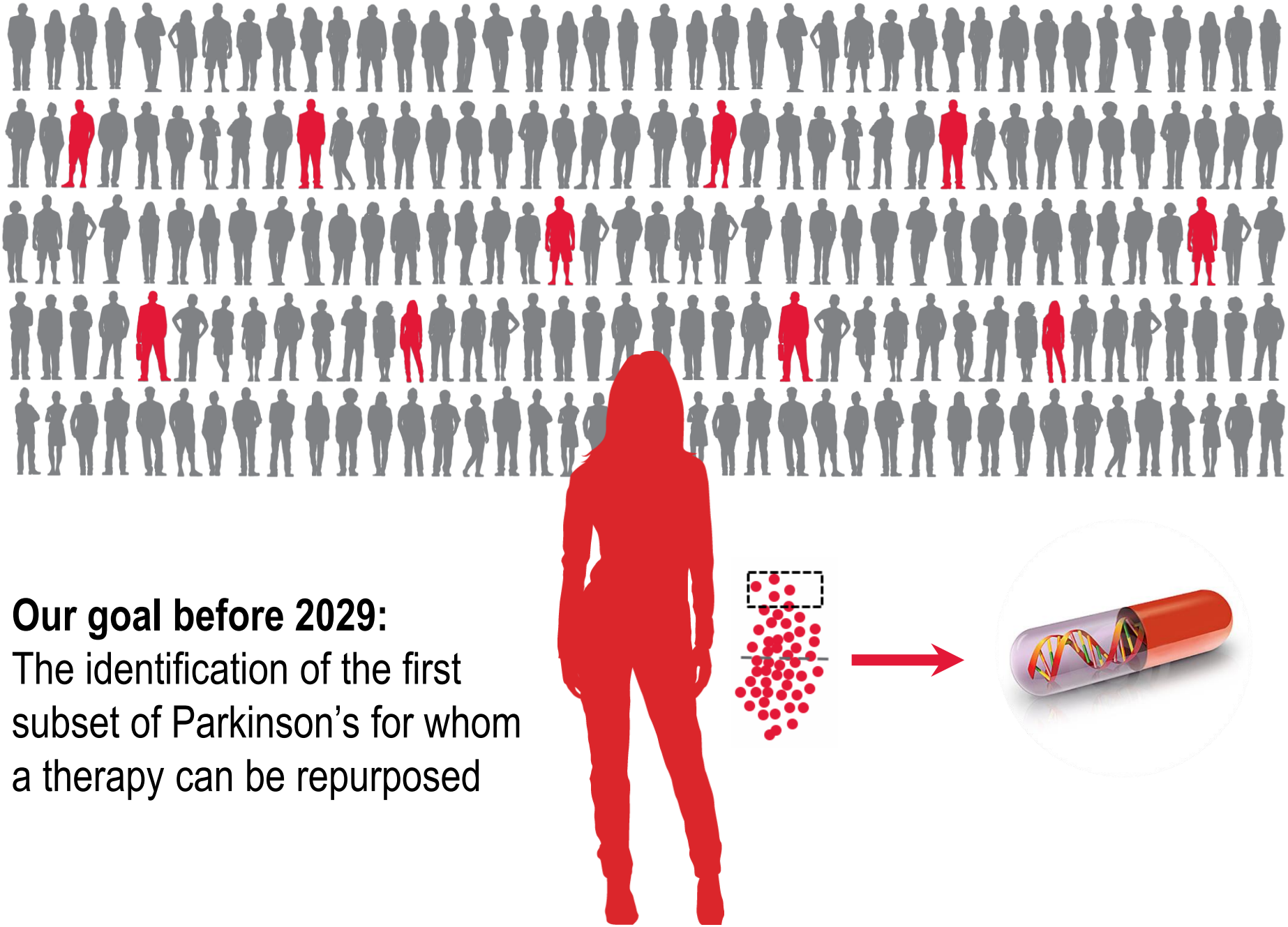
Diagnostic value is limited due to large overlap

Ideal Model of Biomarker Development



Cincinnati Cohort Biomarker Program (CCBP) – Key features

- Inclusive recruitment of patients with Parkinson's, Alzheimer's and related diseases
- Large number of overall participants (target = 5,000)
- High recruitment rate: 18 patients/week
- Annual follow up
- Power to identify small but molecularly suitable subsets for proof-of-concept clinical trials of available drugs with repurposing potential



Our goal before 2029:
The identification of the first subset of Parkinson's for whom a therapy can be repurposed

Building Your Exercise Toolkit

Sarah Krumme Palmer, MS
PWR!® Certified, Rock Steady Boxing Coach
forever*fitness*
sarah@foreverfitnesscincinnati.com

Symptom: Shuffling of Gait

Freezing of Gait

Walking/Gait problems

Why is it important to have good transition or stepping?

Large scale STEPPING in a variety of directions will improve:

- Transfers
- Floor/bed mobility
- Strength
- Help avoid tripping when walking, stepping on/off curbs or stairs
- Increase walking speed
- Reduce shuffling
- Improve overall balance

GOAL:

DECREASE RISK OF FALLS
Maintain Independence

PWR! Step in Sitting

For video reference, go to YouTube.com and search

"PWR! Moves Positions - Sitting"

PWR! Step in Standing

For video reference, go to YouTube.com and search

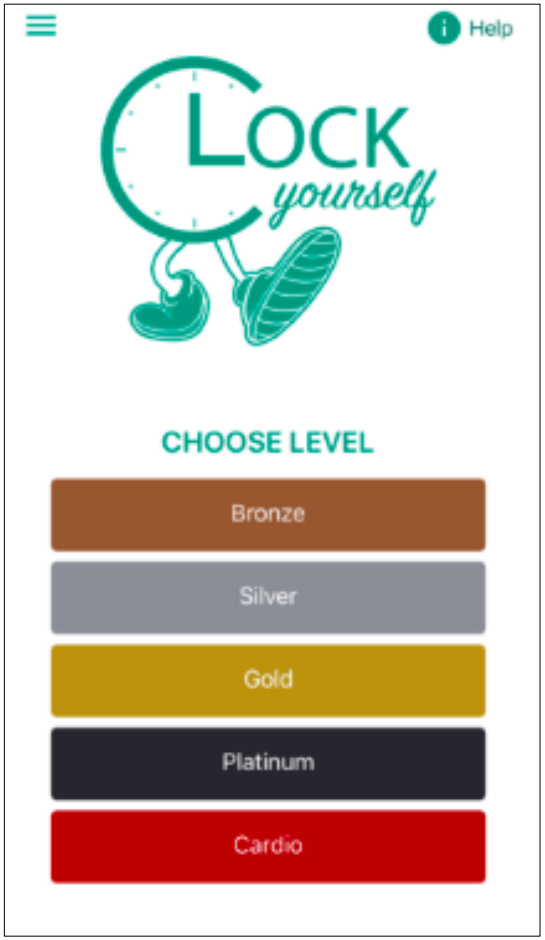
"PWR! Moves Positions - Standing"

Fun way to work on Stepping:

"CLOCK YOURSELF"

= Physical Exercise + Cognitive Exercise (simultaneously) x SPEED

App: $2-3



Benefits of Using Clock Yourself

Consider delete?
Or delete the
next slide?

- Think Faster
- Step Faster: Combats bradykinesia
- Brain Games: Cognitive
- Reaction Time Training: Decrease fall risk
- Can be used for people with all different types of fitness levels
- Can do seated as well as standing
- FUN and FUNctional

PROGRESSION IDEAS

- Alternate step with arm reach
- Scarf to hand and change hand holding scarf each step
- Increase speed for improving reaction time
- Decrease speed for improving balance
- Resistance band or small weights
- Hand flicks, finger stepping
- Vocal and cognitive exercises: say the hour with effort, say the minutes or month
- Try the next levels on Clock Yourself
- Practice stepping (PWR! Steps) in different positions (sit, stand, all 4's, stomach, back – search PWR! Moves on YouTube for video reference

Research Snapshot:

New Basic Research in PD

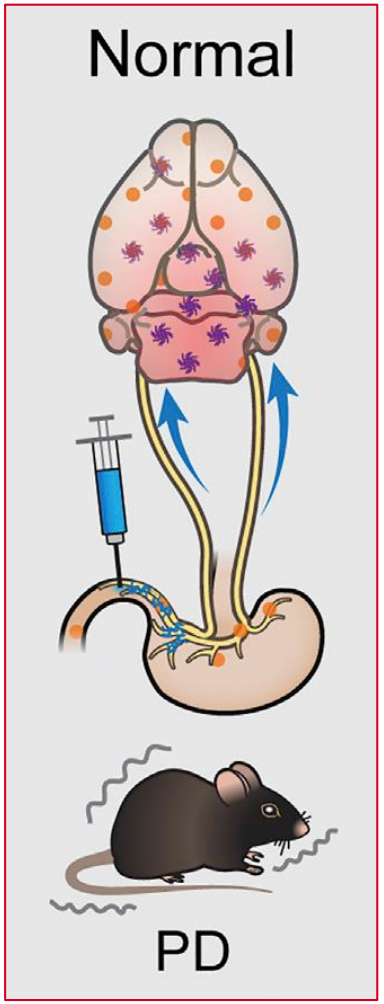
Kim Seroogy, PhD

Professor, UC Department of Neurology

Director, Selma Schottenstein Harris Lab for Research in Parkinson's

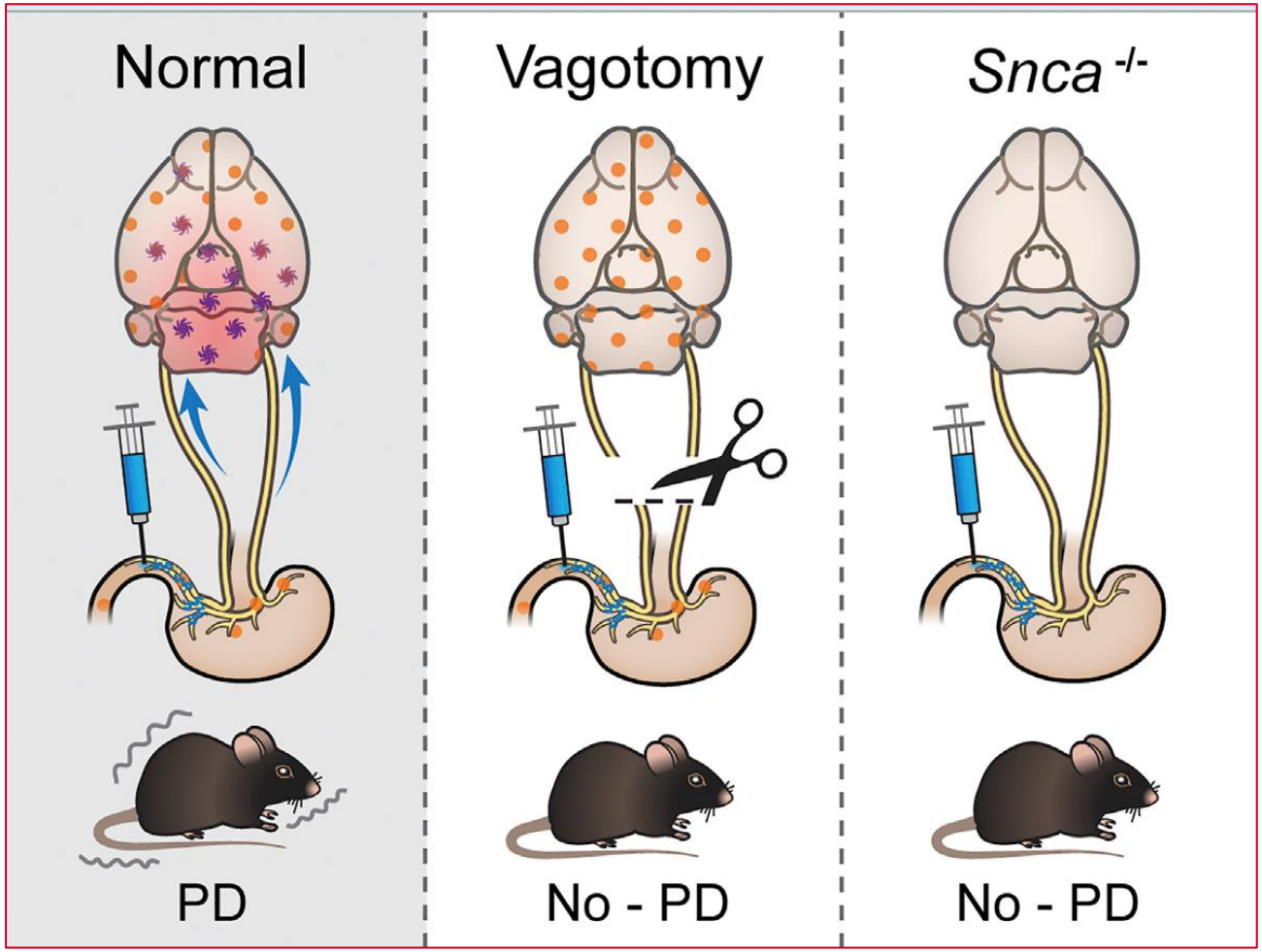
Gut-to-brain model of PD

- Toxic α-synuclein enters the body through the gut, then is transmitted to the nervous system via the vagus nerve
- Dopamine cells degenerate due to this α-synuclein clumping
- Gut injection of toxic α-synuclein causes PD-like motor and non-motor symptoms
- PD-like pathology and symptoms require normal α-synuclein already present in cells



Kim et al., Neuron 2019

Gut-to-brain model of PD

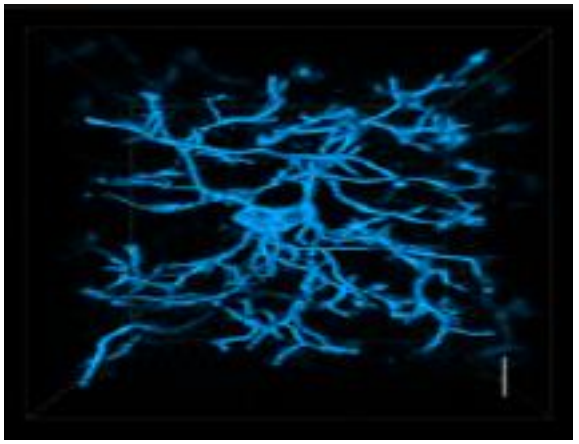


Bottom line: Supports theory that PD can start in gut

Kim et al., Neuron 2019

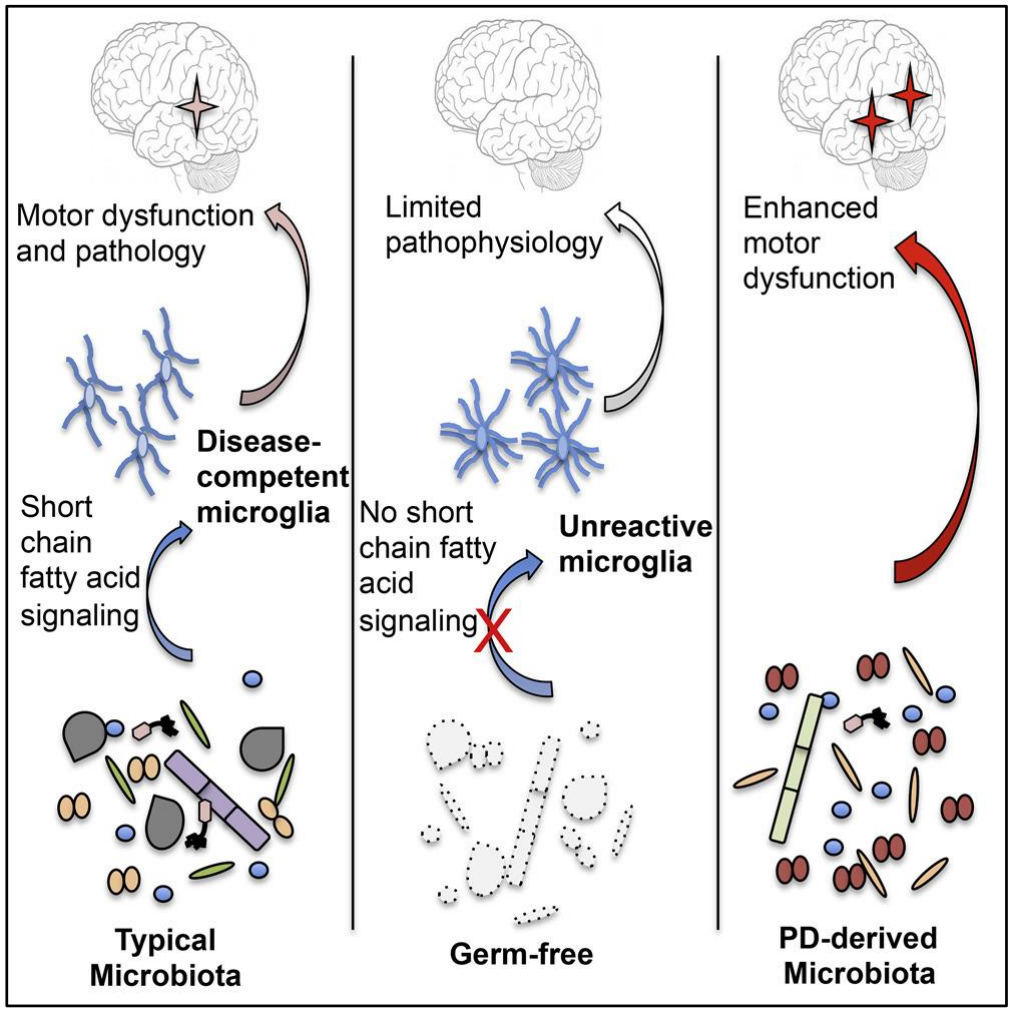
Gut bacteria regulate PD

- Gut microbes promote α-synuclein-mediated motor deficits and brain pathology
- Depletion of gut bacteria reduces brain inflammation
- Molecules called *short chain fatty acids* modulate brain immune cells and enhance PD pathophysiology
- Human gut microbes from PD patients induce enhanced motor deficits in mice



Sampson et al., Cell 2016

Gut bacteria regulate PD

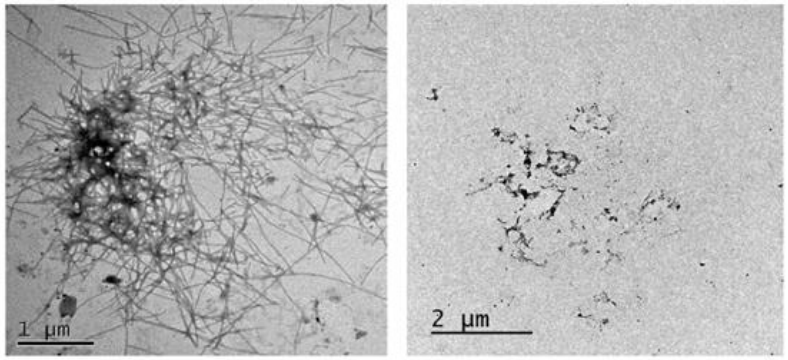


Bottom line:
Signals from gut microbes regulate motor dysfunction and PD pathology in brain.

Sampson et al., Cell 2016

New molecule stops damage to nerve cells

without →



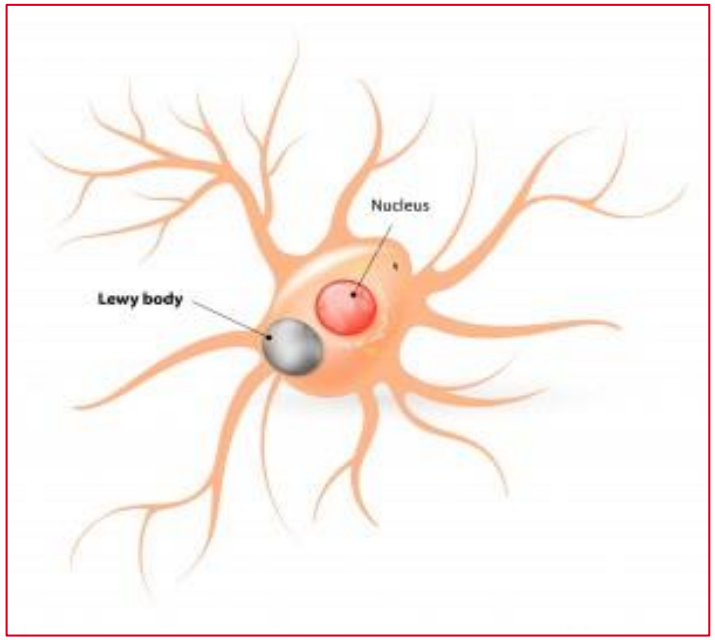
← with

- Small molecule called *SynuClean-D* inhibits α-synuclein clumping
- Screened over 14,000 molecules to identify the new molecule
- *SynuClean-D* rescues dopamine cells from α-synuclein-induced degeneration in an animal model
- Bottom line: *SynuClean-D* may have therapeutic application for treatment of PD

Pujols et al., Proceedings of the National Academy of Sciences 2018

DNA repair, Lewy bodies and PD

- α-synuclein is a DNA-binding protein
- α-synuclein regulates DNA repair in the cell nucleus
- α-synuclein clumping in Lewy bodies reduces its levels in the nucleus, compromising its function



Bottom line: New twist on function of α-synuclein: Unrepaired DNA damage due to decreased α-synuclein in nucleus may trigger cell death as seen in PD.

Schaser et al., *Scientific Reports* 2019

Summary of Basic Research Snapshots

- PD may start in gut and spread to brain
- Gut bacteria regulate PD-related motor deficits and pathology in brain
- New molecule *SynuClean-D* prevents toxic protein clumping & dopamine cell degeneration
- New function for α-synuclein in DNA repair

Panel – Questions and Answers

Moderator: Andrew Duker, MD
Panel: Alberto Espay, MD, MSc
Maureen Gartner, NP-C
Juan Torres-Reveron, MD, PhD
Kim Seroogy, PhD
Sarah Palmer, MS
Cara Jacob, MD