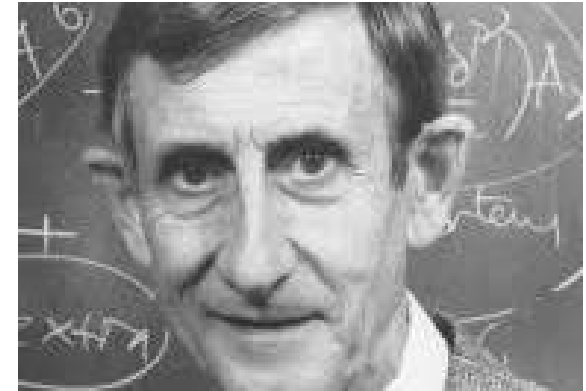


# PD Conference Intro slide

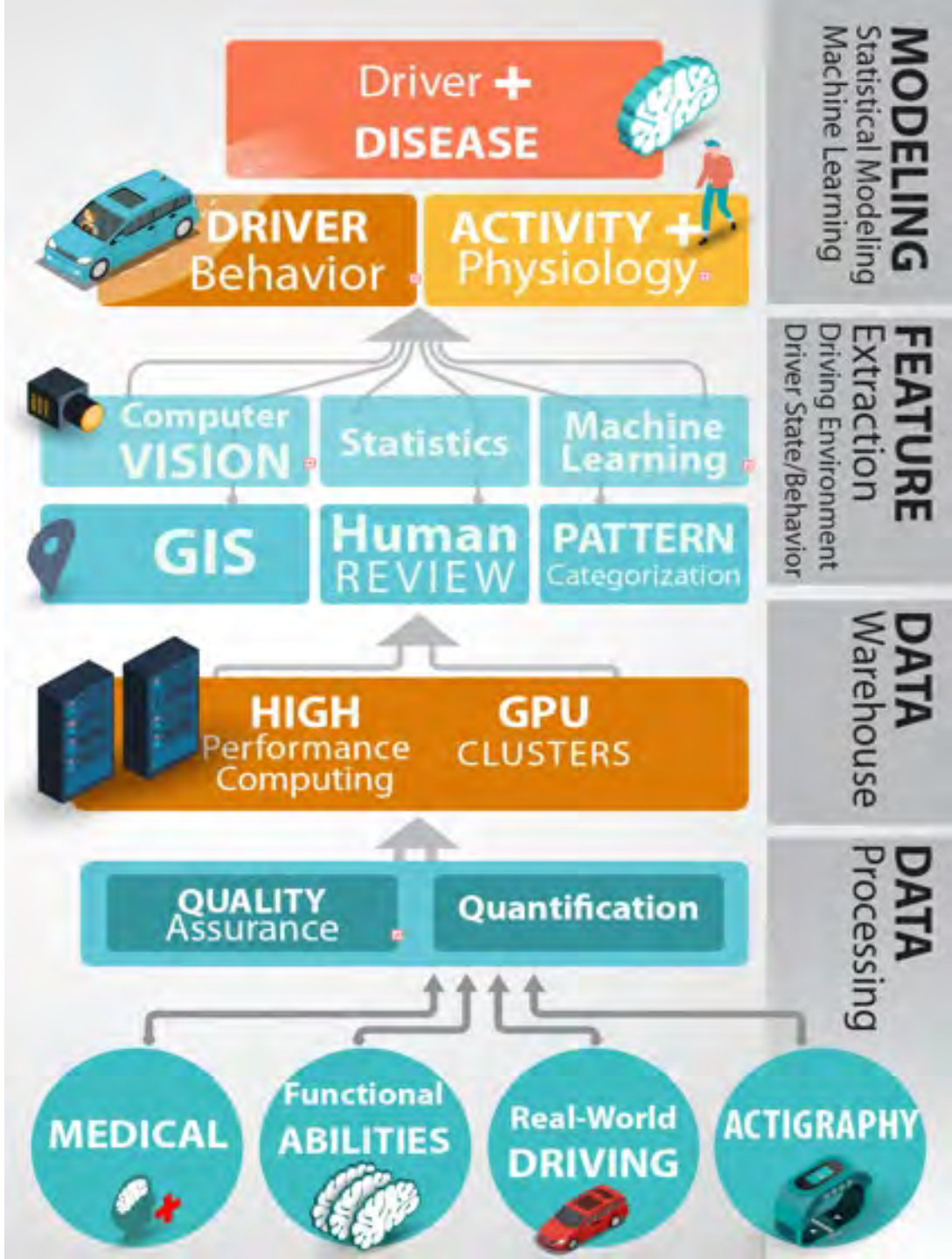
# Tool Driven Revolution



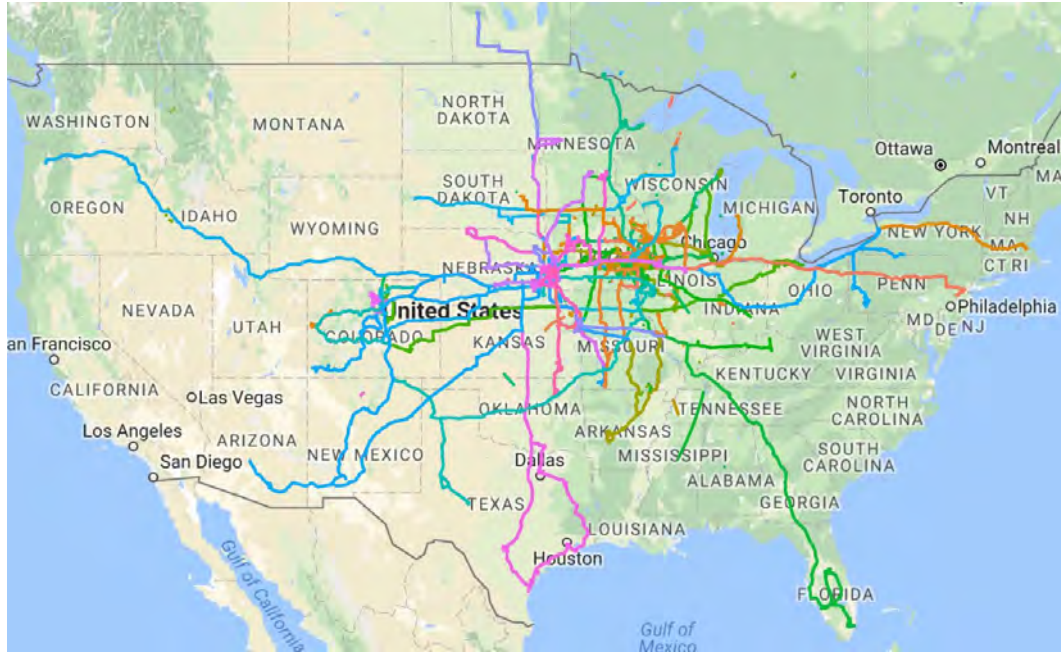
Freeman Dyson (1923-2020)

*"New directions in science are launched by new tools much more often than by new concepts. The effect of a concept-driven revolution is to explain old things in new ways. The effect of a tool-driven revolution is to discover new things that have yet to be explained."*





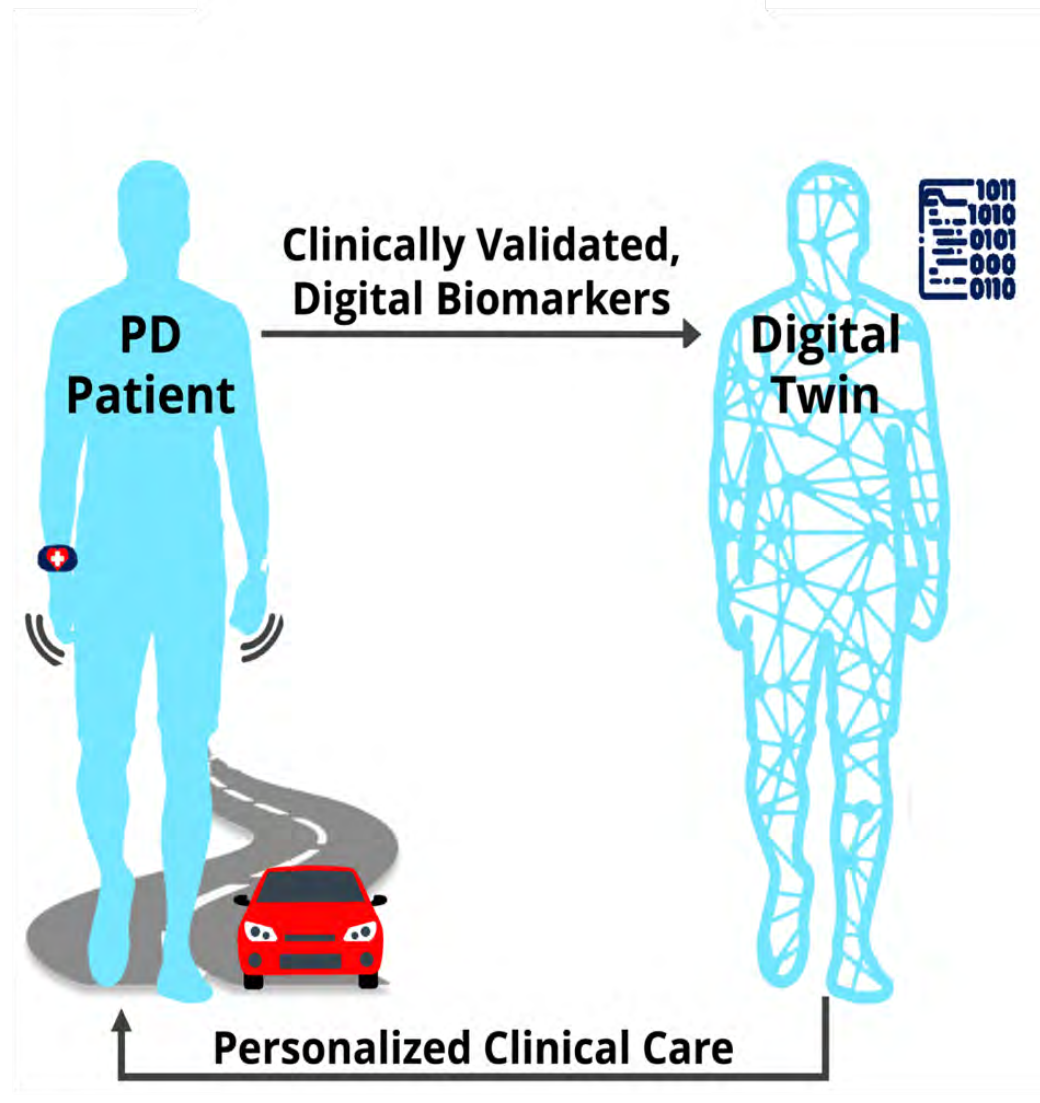
Modern research data flow integrating classical statistics and AI



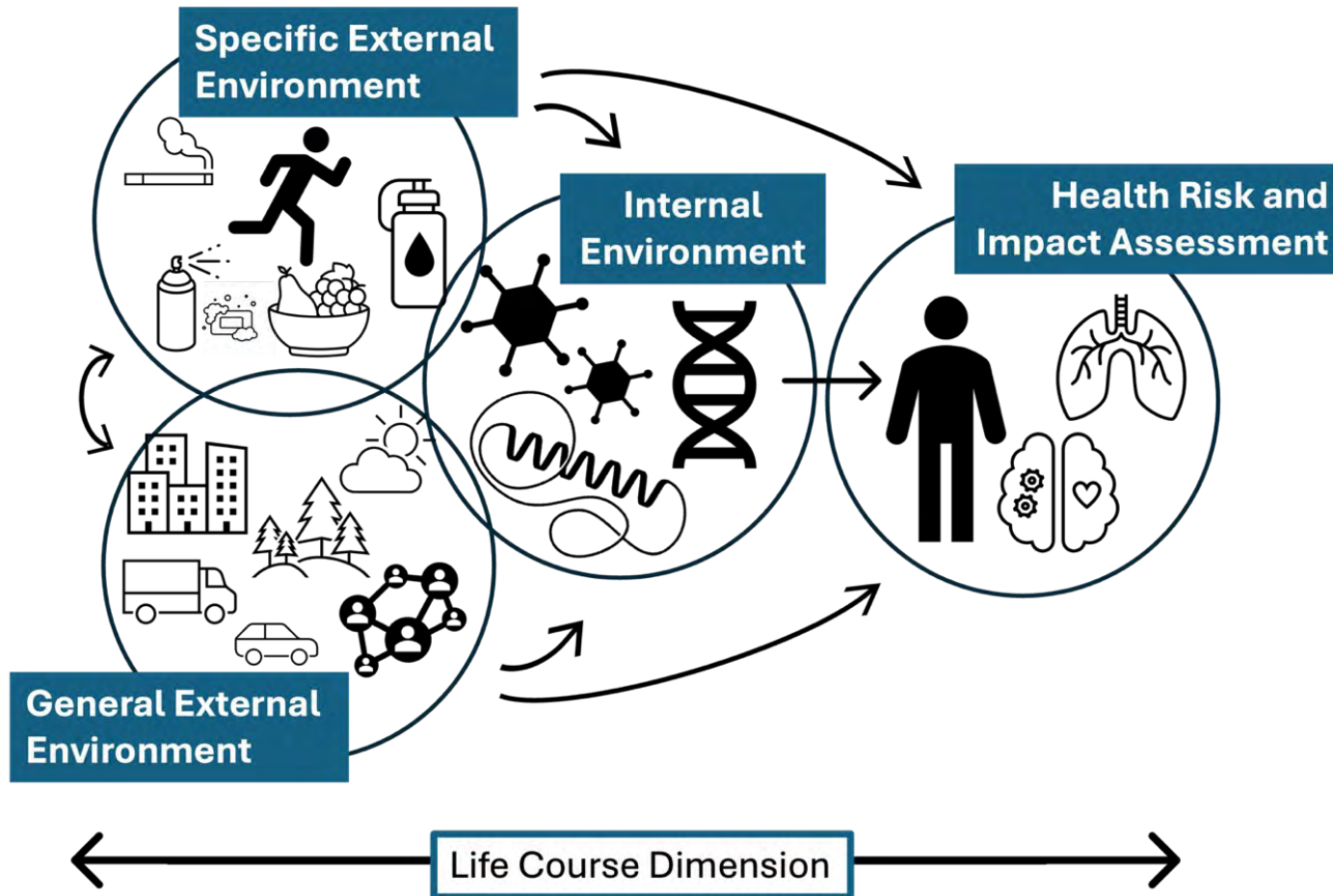
A million miles, >500 drivers



# Digital twins



# The exposome



**Ubiquitous sensors** (in devices, vehicles, buildings, homes, appliances, clothing, people, and across cities) among an "internet of things" (**IoT**) are continuously monitoring people's **performance, behavior, and physiology** in varying social and **environmental** contexts (e.g., air, water, sound, light, weather, geography).

These data can be combined **with self-reports and ecological momentary assessments** (experience sampling) on cognitive, emotional, and conative status, and "**-omics**" **data**, providing unprecedented observations of the health "in the wild".

Transition slide

# Diagnosis and Management of Parkinson's Disease

Miguel Situ-Kcomt, MD  
Assistant Professor  
Movement Disorders Division  
Department of Neurological Sciences



University of Nebraska  
Medical Center<sup>SM</sup>





# Summary

## Diagnosis:

- Clinical Features
- DaTScan (?)
- Skin Biopsy (?)
- Cerebrospinal fluid test (?)

## Management:

- Medication Therapy
- New approved therapies



# Diagnosis



# Risk Factors

- Genetics
- Environmental Risk Factors
- Exposure to certain chemicals
- Gut flora & Diet (?)
- We are living longer!



# Clinical Features

Our rationale is based on two scales:

**1988-1992 - UK Parkinson's Disease Society Brain Bank  
Clinical Diagnostic Criteria (UKPDSBB)**

**1999 – Gelb's Diagnostic Criteria for PD**

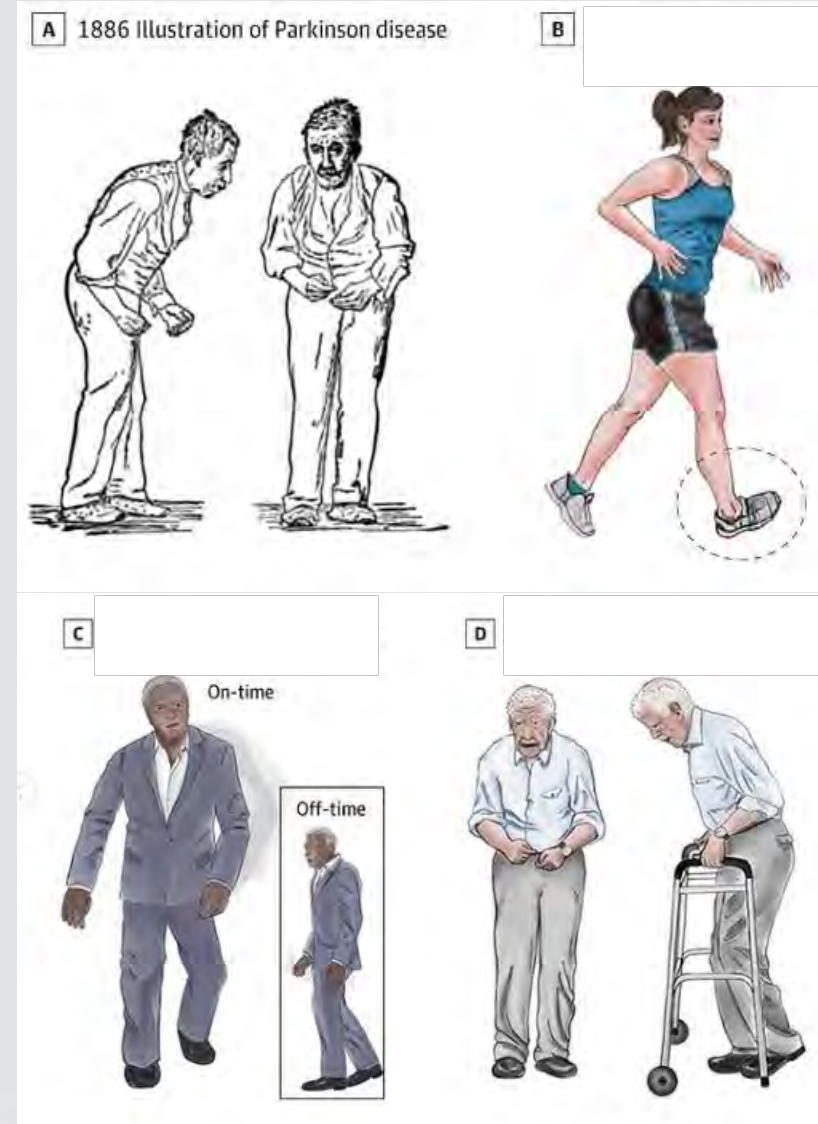


# Clinical Features

Bradykinesia (slowness of movement)

**AND at least one of the following**

- Resting tremor (4-6 Hz in frequency)
- Muscular Rigidity
- Postural Instability





## **Step 2 Exclusion criteria for Parkinson's disease**

- history of repeated strokes with stepwise progression of parkinsonian features
- history of repeated head injury
- history of definite encephalitis
- oculogyric crises
- neuroleptic treatment at onset of symptoms
- more than one affected relative
- sustained remission
- strictly unilateral features after 3 years
- supranuclear gaze palsy
- cerebellar signs
- early severe autonomic involvement
- early severe dementia with disturbances of memory, language, and praxis
- Babinski sign
- presence of cerebral tumor or communication hydrocephalus on imaging study
- negative response to large doses of levodopa in absence of malabsorption
- MPTP exposure

## **Step 3 supportive prospective positive criteria for Parkinson's disease**

Three or more required for diagnosis of definite Parkinson's disease in combination with step one

- Unilateral onset
- Rest tremor present
- Progressive disorder
- Persistent asymmetry affecting side of onset most
- Excellent response (70-100%) to levodopa
- Severe levodopa-induced chorea
- Levodopa response for 5 years or more
- Clinical course of ten years or more



# Clinical Features

Gelb's study contribution was describing a level of **diagnostic certainty**

**BECAUSE ULTIMATELY A TRUE DIAGNOSIS IS NOT SET IN STONE**

**Table 2. Proposed Diagnostic Criteria for Parkinson Disease**

Criteria for POSSIBLE diagnosis of Parkinson disease:

At least 2 of the 4 features in Group A\* are present; at least 1 of these is tremor or bradykinesia

**and**

**Either** None of the features in Group B\* is present

**Or** Symptoms have been present for less than 3 years, and none of the features in Group B\* is present to date

**and**

**Either** Substantial and sustained response to levodopa or a dopamine agonist has been documented

**Or** Patient has not had an adequate trial of levodopa or dopamine agonist

Criteria for PROBABLE diagnosis of Parkinson disease:

At least 3 of the 4 features in Group A\* are present

**and**

None of the features in Group B\* is present (note: symptom duration of at least 3 years is necessary to meet this requirement)

**and**

Substantial and sustained response to levodopa or a dopamine agonist has been documented

Criteria for DEFINITE diagnosis of Parkinson disease:

All criteria for POSSIBLE Parkinson disease are met

**and**

Histopathologic confirmation of the diagnosis is obtained at autopsy (see Table 3)

\*Group A and Group B are detailed in Table 1.



# Clinical Features

## Limitations:

- Too focused on motor criteria as cardinal features.
- Lack of depth in non-motor features, particularly cognition.
- No consideration for genetics.
- Does not address the question of prodromal symptoms.
- **No biological marker.**





# Can we test Parkinson's Disease?



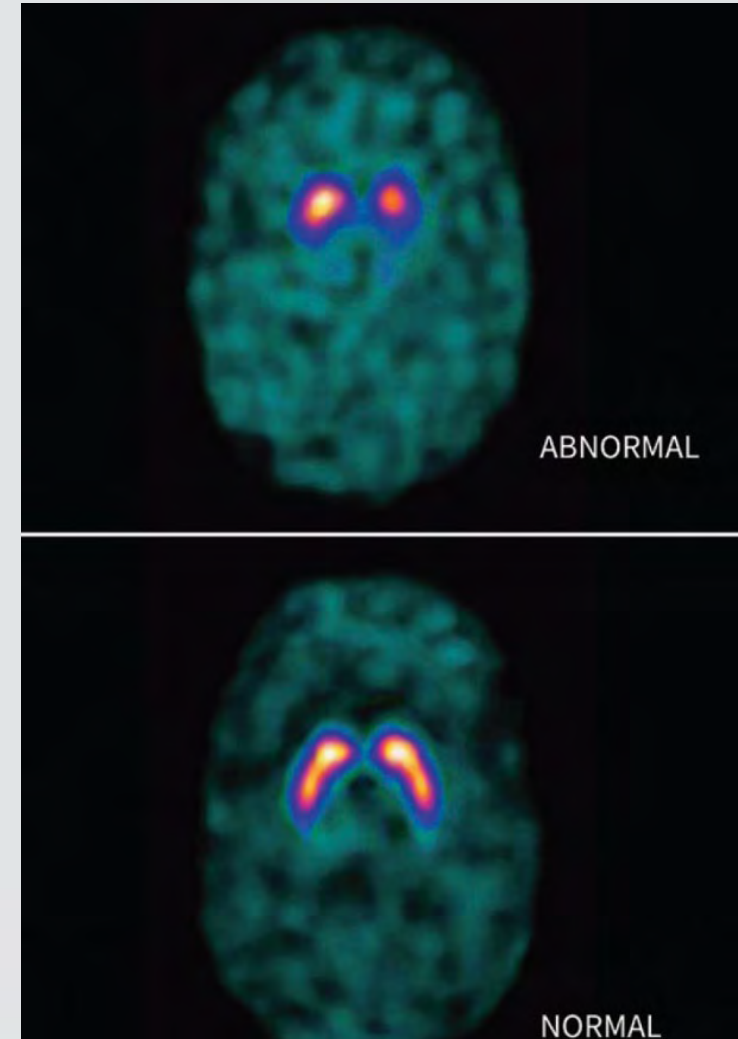
# Dopamine Transporter Scan (DaT Scan)

Approved in the US since 2011

Checks for dopamine innervation in the brain – analyzed qualitatively

If positive – You have a primary deficit of dopamine.

**DOES NOT DIAGNOSE PD**





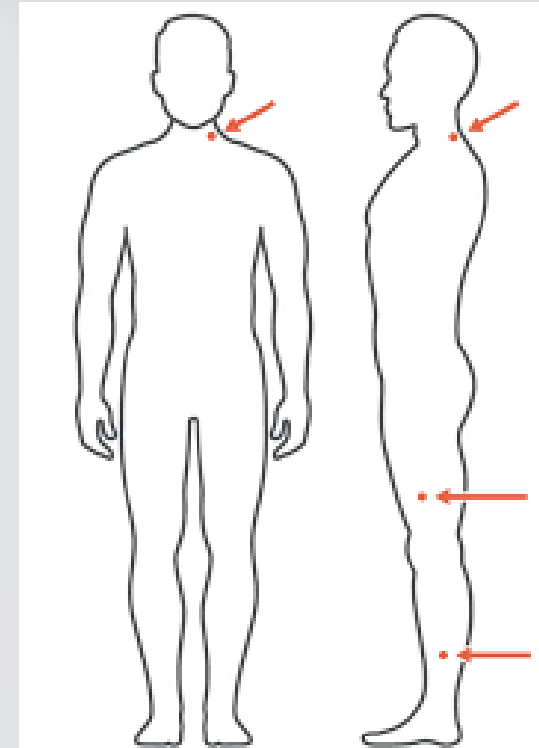
# Skin Biopsy

The Syn-One Test<sup>®</sup> by CND Life Sciences (since 2022)

Detects phosphorylated alpha-synuclein (aSynP) deposition in the tissue.

- 92.7% in PD
- 98.2% in MSA
- 96% in DLB
- 100% in Pure Autonomic Failure
- 3.3% in healthy controls

**IF POSITIVE – you have aSynP deposition...  
but not necessarily PD.**





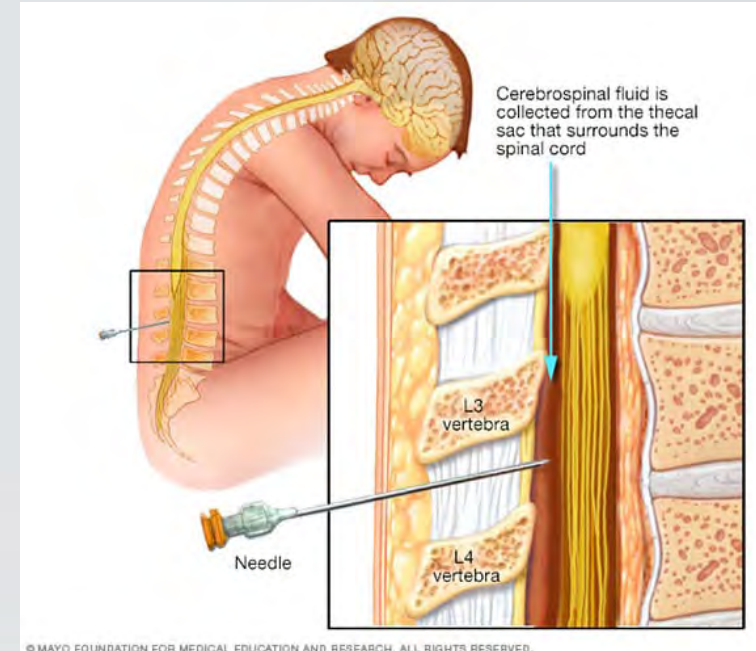
# Lumbar Puncture Testing

Cerebrospinal Fluid (CSF) Alpha-Synuclein Testing by Seed Amplification Assay (since 2021)

Takes a sample of CSF, checks for the misfolded protein and if present, amplifies it to detect it

Results are qualitative: **Present or Absent**

**IF POSITIVE – You have misfolded protein... but not necessarily PD.**





# Pros & Cons

- All may aid in diagnosing a primary parkinsonism.
- Skin and CSF testing may aid in detecting alpha-synuclein, which is commonly found in PD but also in other diseases (DLB, MSA, PAF).
- **NONE OF THEM CONFIRM PD**
- **NONE OF THEM HELP US STAGE PD (how far advanced)**



# Management of PD





# Initial Management

Levodopa therapy

Other medications:

- Dopamine agonists
- Rasagiline



PT/OT/SLP – Afternoon presentations!

**Exercise if able!**



# Levodopa

Sinemet 25/100 (or Sinemet IR 25/100)

Sinemet 25/250

Sinemet CR 25/100 or 50/200

Rytary (carbidopa-levodopa ER)

Duopa (Intestinal Gel)

Inbrija (On-demand Inhaler)

## **Discontinued:**

Parcopa (since December 2022)



# Other medications

## Dopamine Agonists:

- Pramipexole (Mirapex)
- Ropinirole (Requip)
- Rotigotine (Neupro patch)
- Apomorphine [on-demand] (Apokyn)

## COMT Inhibitors:

- Entacapone (Comtan)
- Tolcapone (Tasmar)
- Opicapone (Ongentys)

## MAO Inhibitors:

- Rasagiline (Azilect)
- Selegiline (Eldepryl)

## Anti-cholinergics:

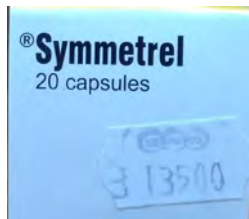
- Trihexyphenidyl (Artane)
- Benztropine (Cogentin)

# Other medications



## Istradefylline (Nourianz)

- Helps with OFF periods



## Amantadine (Symmetrel, Gocovri, Osmolex ER)

- Has been used as monotherapy before
- Mainly used for dyskinesias



# New kids on the block

...More levodopa!

**Crexont** – New version of extended-release levodopa.





# New kids on the block

## Vyalev – Subcutaneous levodopa pump

- Can deliver up to 2500mg daily of levodopa in 24 hours
- Reversible procedure
- Needs to be refilled daily







**THANK YOU!**



UNIVERSITY OF  
**Nebraska**  
Medical Center



# Research Updates in Parkinson's Disease

**Erin L. Smith**

Assistant Professor

Movement Disorders Division



University of Nebraska  
Medical Center™



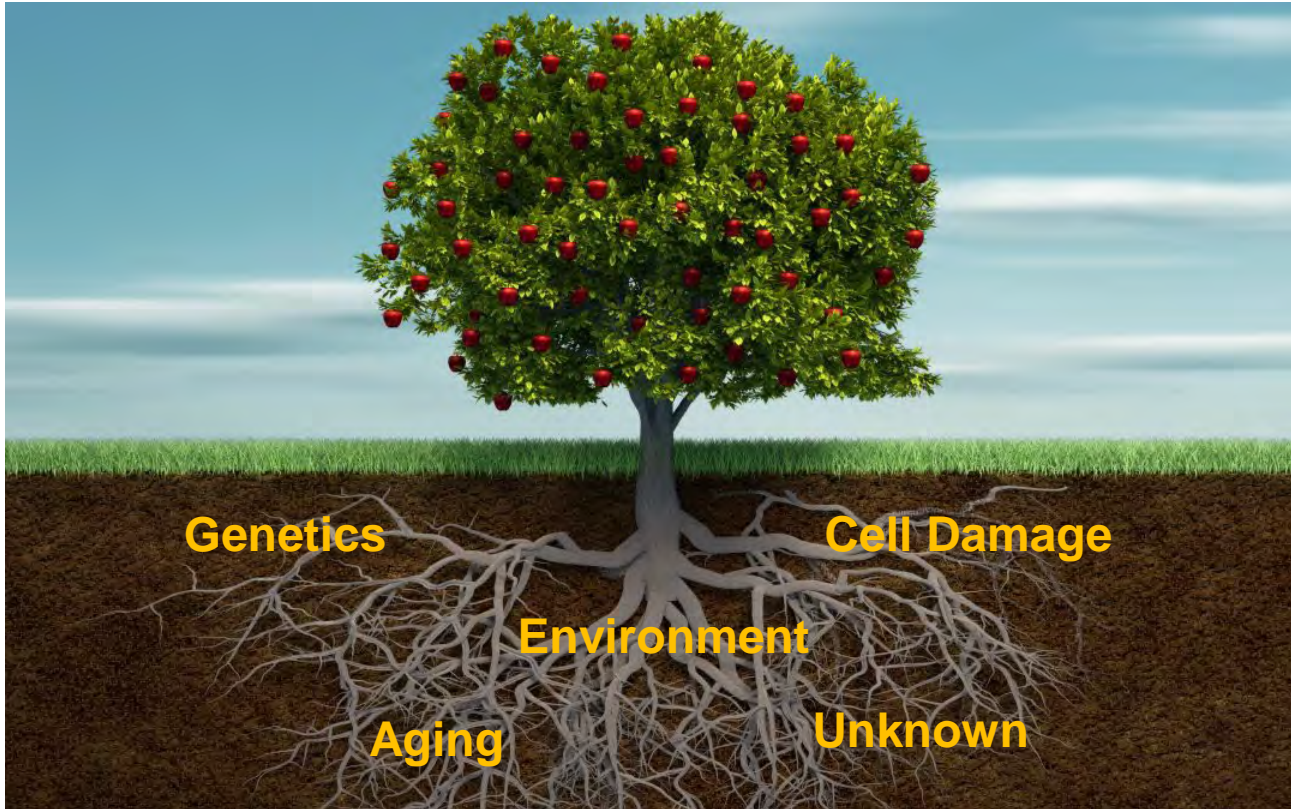
# Why is Research Important?

- 2nd most common neurodegenerative disease
  - After Alzheimer's Dementia
- \$14 billion cost of treatment annually
  - Loss of productivity: \$6.3 billion



**We still don't have a *cure***

# The “cure” isn’t so straightforward





Journal of Parkinson's Disease 14 (2024) 899–912  
DOI 10.3233/JPD-240272  
IOS Press

899

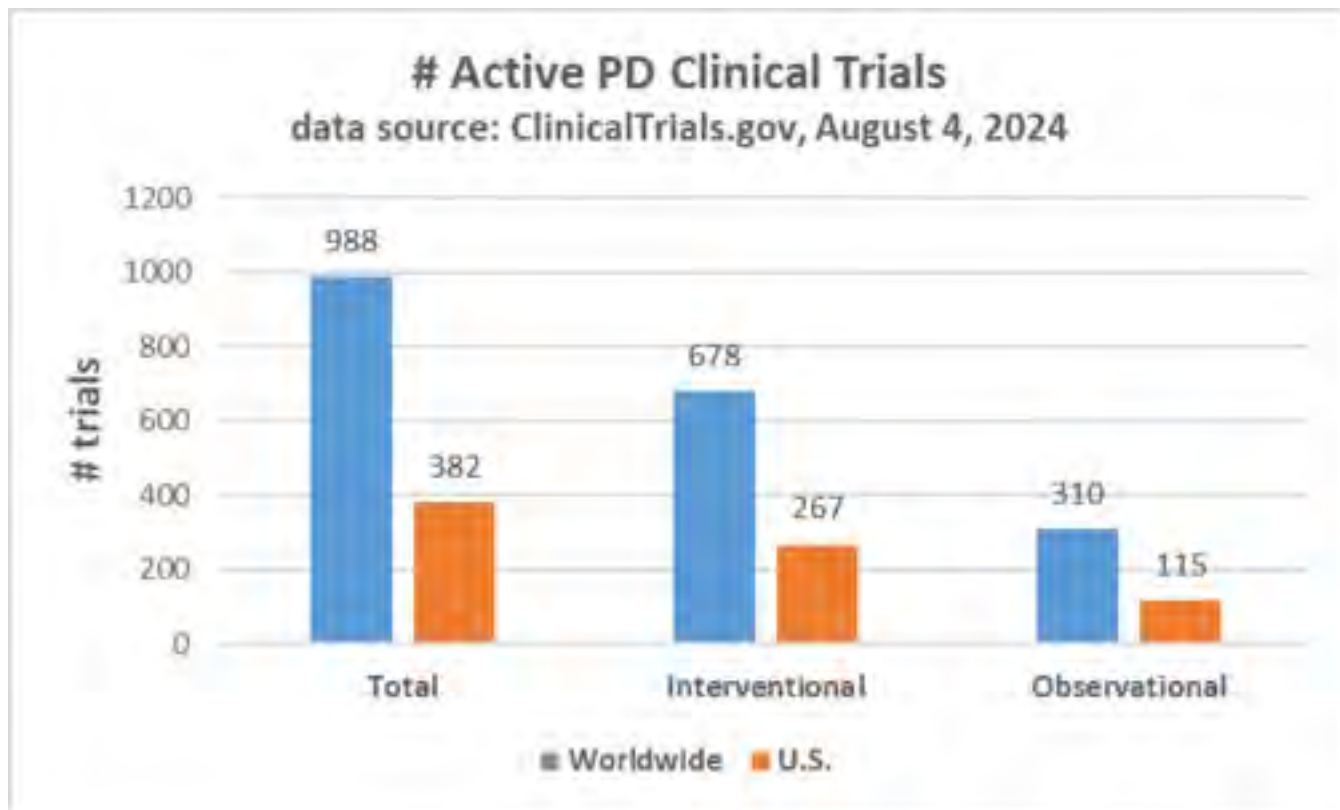
## Clinical Trial Highlights

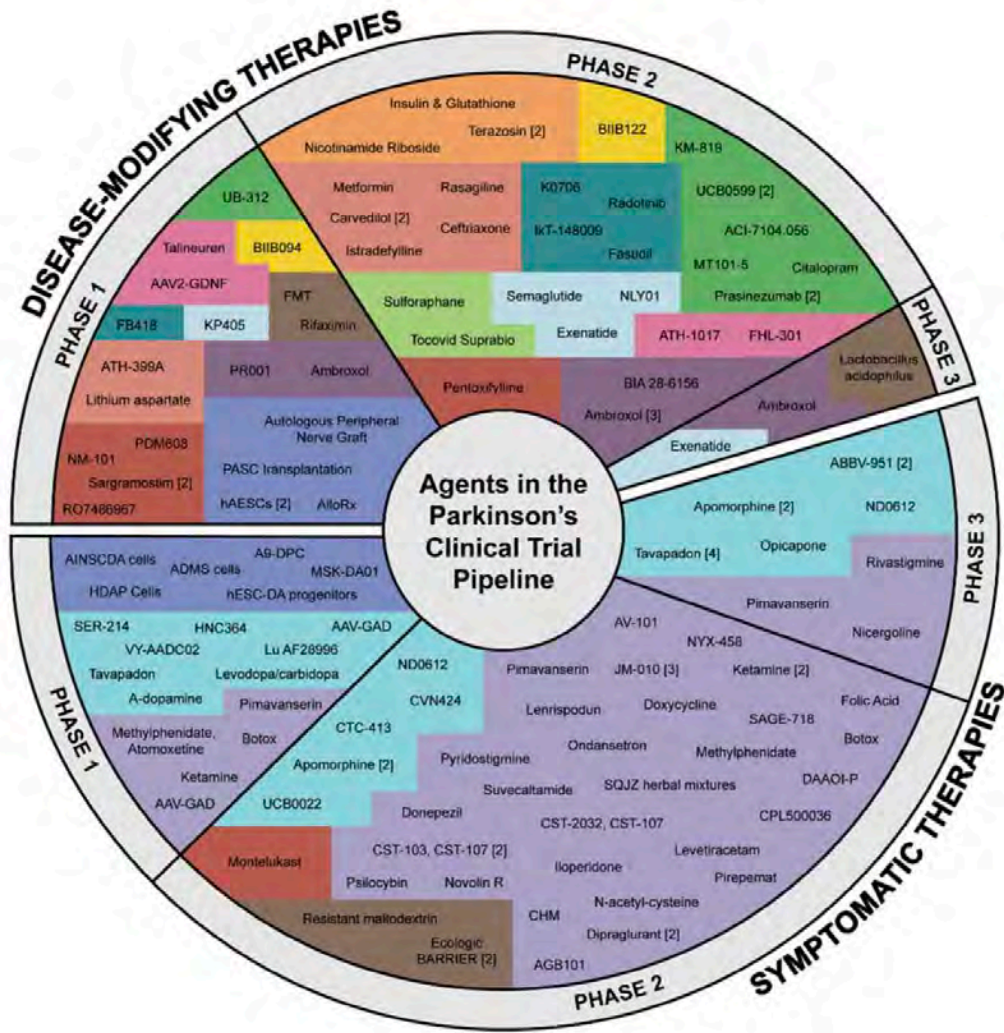
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# Parkinson's Disease Drug Therapies in the Clinical Trial Pipeline: 2024 Update



# PDTrialTracker.info





- Therapy Targets**
- Anti-inflammatory
  - Antioxidant
  - Cell Therapy
  - DMT Other
  - Dopaminergic Symptom Relief
  - Energy and Mitochondria
  - GBA
  - GLP-1R Agonist
  - Kinase Inhibitor
  - LRRK2
  - Microbiome/GIT
  - Non-dopaminergic Symptom Relief
  - Targeting aSN
  - Neurotrophic Factors



# Today's Topics

1. Finding A **Cure**
  1. Disease Modifying Therapies
2. Symptom-**Specific** Treatments
  1. Improving Quality of Life
3. Emerging **Biomarkers**
  1. Diagnosing PD Earlier
4. Future **Directions**
5. How You Can **Get Involved**





# **The Quest for A Cure: Disease-Modifying Therapies (DMTs)**

# What Does Disease-Modifying Mean?



## Disease Modifying (DMT)

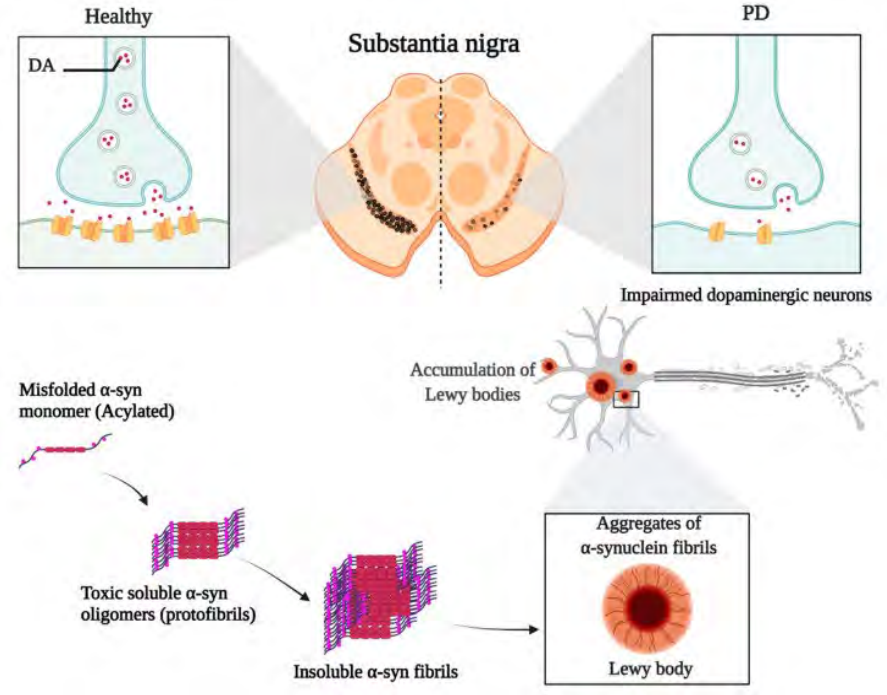
Slows or stops the progression and neuronal cell death

## Symptomatic Therapy (ST)

Improves or restores function for the patient

# How A Cure Might Work

- Alpha synuclein targets
- Glucagon-like peptide (GLP-1) agonists
- Antioxidants
- Anti-inflammatories
- Gut/Microbiome
- Gene-specific
  - GBA
  - LRRK2





# Quick Review: What's Happening in the Parkinson's Brain

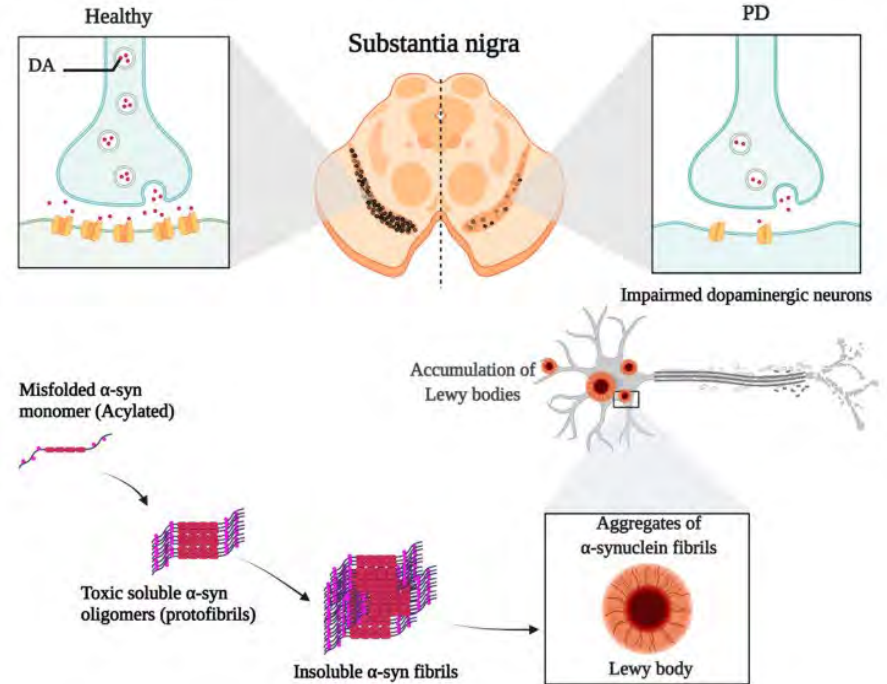


The brain makes a protein called **alpha-synuclein**

Protein misfolds while being made

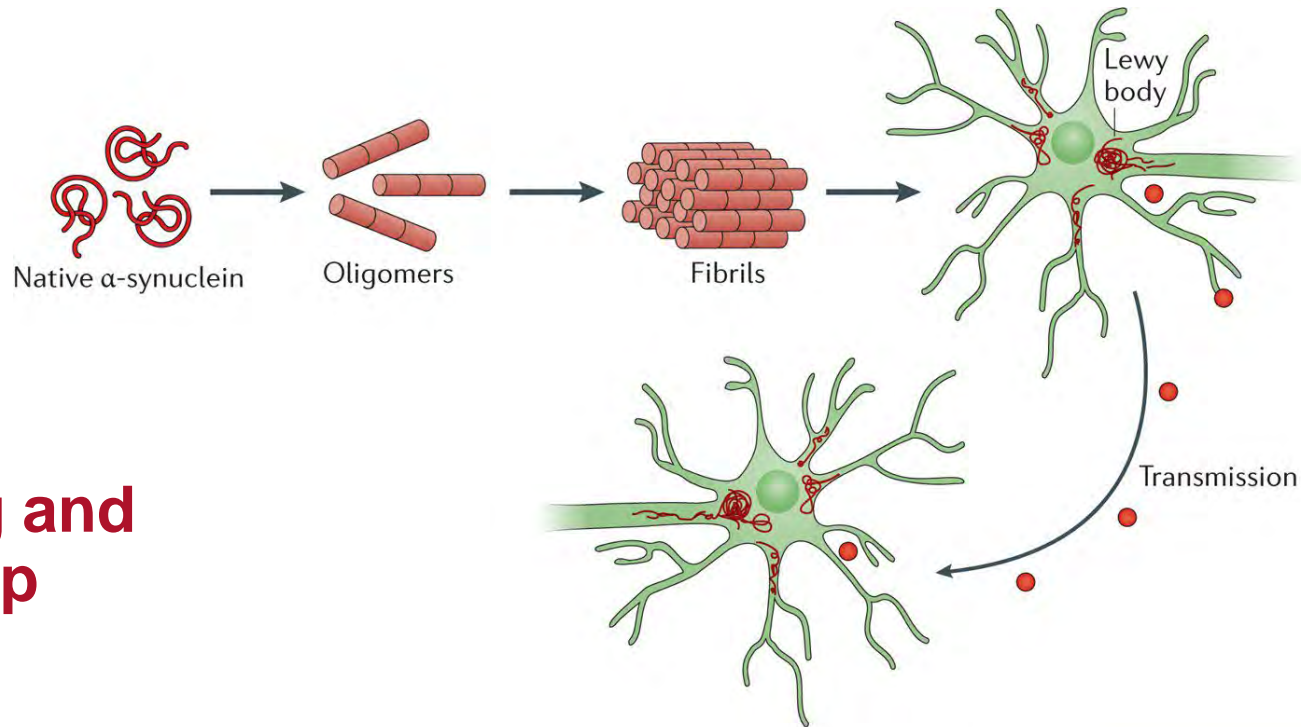
→ Builds up in the brain and becomes **toxic**

→ Kills off **dopamine cells** and causes Parkinson's Disease





# Alpha Synuclein Therapies



Goal:

**Stop misfolding and  
toxic build-up**

# Alpha Synuclein Therapies

- Give or create **antibodies against**  $\alpha$ -synuclein
  - Through IV
  - As a vaccine
- Block  $\alpha$ -synuclein
- Break down misfolded  $\alpha$ -synuclein

*Caveat: Not every PD has an alpha-synuclein problem*





# PASADENA Trial: Prasinezumab

- Antibody = a natural “fighter” in the body
- Binds to abnormal alpha-synuclein protein
- Cleans out the bad protein

**October 2024:**

**Phase II PASADENA Trial**

“Less progression of motor symptoms by **up to 40%**”

**Next Steps:**

**Phase II Trial (PADOVA)  
on-going**



# Can a Cough Medicine Cure PD?

## Ambroxol

- Cough medicine used on 50+ countries
  - **NOT** FDA approved in the US
- Enzyme tied to specific genetic mutation (GBA)
  - **Clears alpha-synuclein**





# Can a Cough Medicine Cure PD?

## Ambroxol

### ASPro-PD Trial

- Ambroxol vs Placebo
- Patients **with and without** the GBA genetic mutation

**Next Steps:**  
**Now recruiting in the UK**  
**2023-2027**



Mullin S, Smith L, Lee K, et al. Ambroxol for the Treatment of Patients With Parkinson Disease With and Without Glucocerebrosidase Gene Mutations: A Nonrandomized, Noncontrolled Trial. *JAMA Neurol.* 2020;77(4):427–434. doi:10.1001/jamaneurol.2019.4611





# Hot Topic: GLP-1 Agonists

## Ozempic-like drug may help slow the progression of Parkinson's symptoms

Written by [Finn Cohen](#) on April 9, 2024 — Fact checked by [Hannah Flynn](#)



April 19, 2024

## Are GLP-1 Diabetes Drugs Like Ozempic Coming For Parkinson's Disease?

By [Michael S. Okun](#)





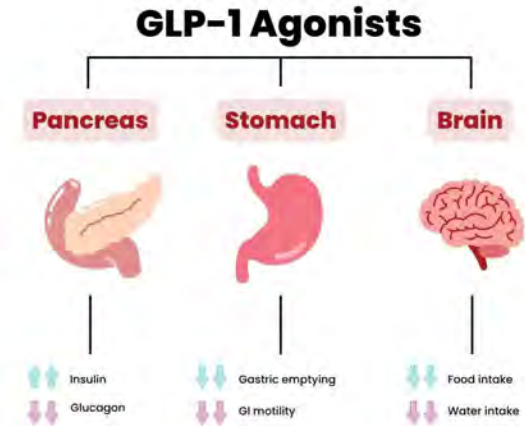
# Diabetes Medications: GLP-1 Agonists

- Trigger insulin release
  - Used for diabetes and weight loss
  - Receptors also in the brain



**GLP-1 agonists may block brain's "inflammatory response"**

**NOTE: Ozempic, Mounjaro, Wegovy do NOT cross into the brain!**

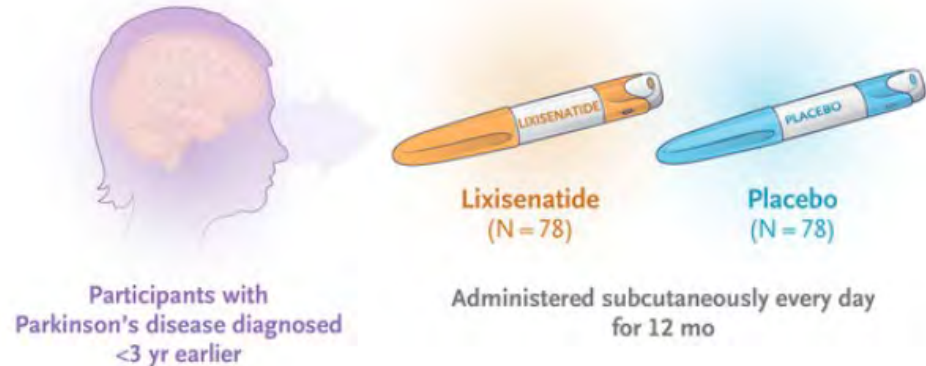


# Diabetes Medications: GLP-1 Agonists

## LIXIPARK Phase 2 Trial

Drug: *Lixisenatide*

- Early PD patients
  - Compared patients getting drug vs placebo group
- Followed 1 year
- Less progression of “motor disability” than placebo



**Authors:** Wastlios G. Meissner, M.D., Ph.D., Philippe Remy, M.D., Ph.D., Caroline Giordana, M.D., David Malt e, M.D., Pascal Derkinderen, M.D., Ph.D., Jean-Luc Houeto, M.D., Mathieu Anheim, M.D., Ph.D., [437](#), for the LIXIPARK Study Group\* Author Info & Affiliations

Published April 3, 2024 | N Engl J Med 2024;390:1176-1185 | DOI: 10.1056/NEJMoa2312323  
VOL. 390 NO. 13 | Copyright   2024

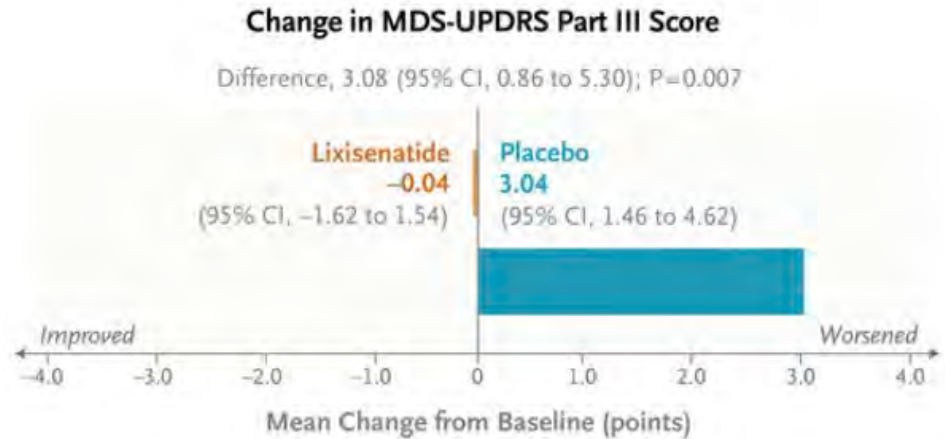


# Diabetes Medications: GLP-1 Agonists

- Medication group stayed stable
- Placebo group worsened

## *Major side effects:*

- *Nausea*
- *Vomiting*
- *Acid reflux*



**Next Steps:**  
**Phase 2 & 3 Trials**  
**Testing on Larger Groups for a**  
**Longer Time**



# Hot Topic: Stem Cells

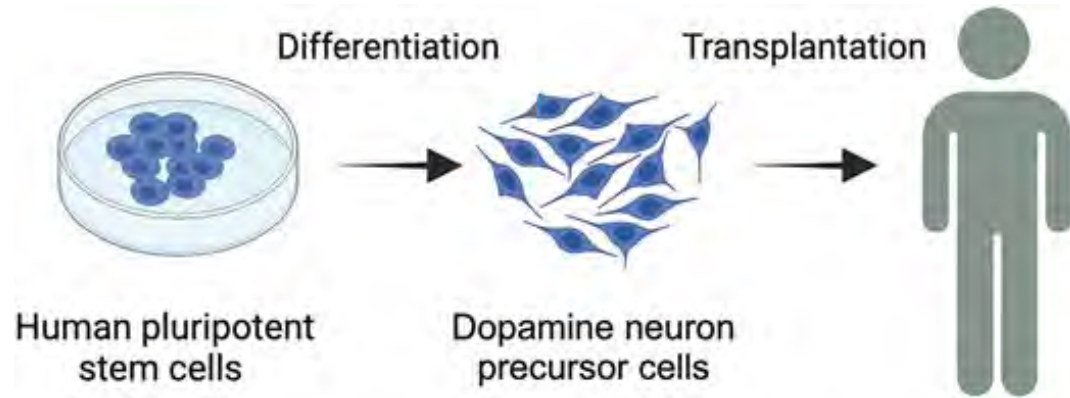


# Stem Cells and PD

“New” cells that can be turned into any type of body cell  
→ Make new brain cells (neuron)

How They Work:

1. *Reduce inflammation*
2. *Regulate immune system*
3. *Restore normal brain cell function*
4. *Promote making new cells*





# Stem Cells and PD



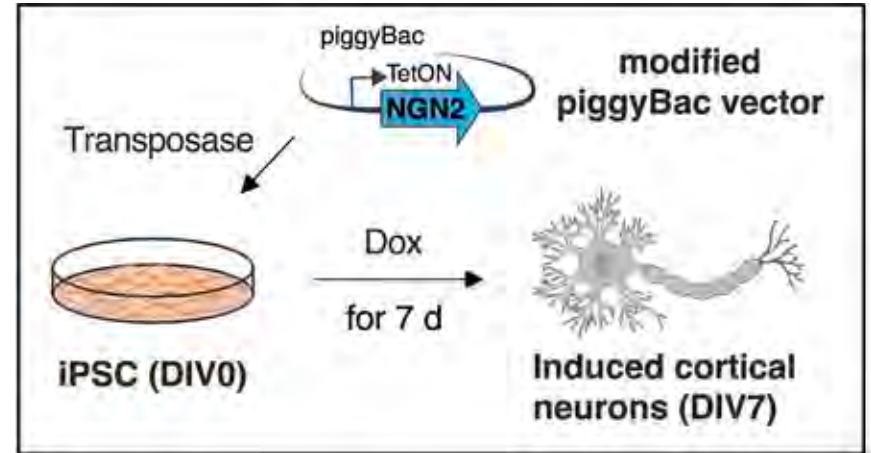
Uses:

## 1. “Model” Parkinson’s for research use

1. (ie) “Parkinson’s in a petri dish”
2. Study new treatments without risking harm to real patients

## 2. Treatment

1. Make new dopamine brain cells
2. Give them to PD patients





# Stem Cell Clinical Trials

Sponsor	Type	Cells	Trial stage	Clinical progress
Kyoto University/ CiRA/Sumitomo	Allogeneic	One iPSC line (HLA matched and unmatched to recipients). Requires immunosuppression	PMMA clearance 2018	Phase I initiated
Sloan Kettering/ BlueRock Therapeutics/Bayer	Allogeneic	Embryonic stem cell line (WA09/H9). Requires immunosuppression	FDA clearance January, 2021	Phase I safety trial completed August 2023. Phase II proposed for 2024
Lund University/ StemPD/Novo Nordisk	Allogeneic	Embryonic stem cell line (RC17). Requires immunosuppression	Swedish Medical Products Agency November, 2022	Phase I initiated
Scripps Research/ Aspen Neuroscience	Autologous	Patient-specific iPSCs. Does not require immunosuppression	FDA clearance August, 2023	Phase I initiated

Branden J Clark, Mariah J Lelos, Jeanne F Loring, *Advancing Parkinson's disease treatment: cell replacement therapy with neurons derived from pluripotent stem cells*, *Stem Cells*, Volume 42, Issue 9, September 2024, Pages 781–790, <https://doi.org/10.1093/stmcls/sxae042>



# Stem Cells & PD

## Limitations & Barriers

- Finding a high enough dose that works **without** causing side effects
- Transplant “matching”
- Graft-induced dyskinesias

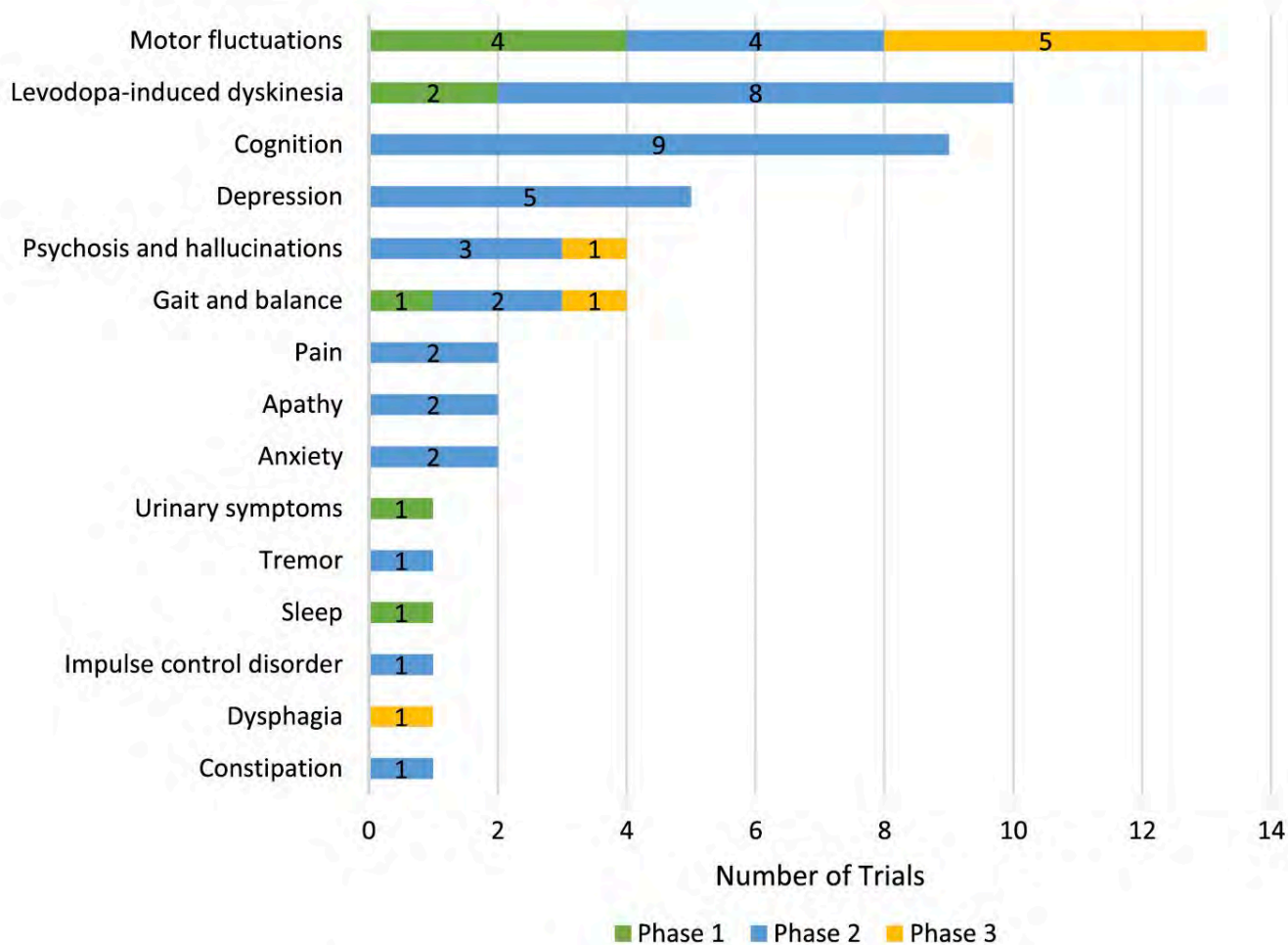
## *Next Steps:*

*Many more studies needed  
Likely will be years ahead*

***Stem Cell Therapy is NOT  
an FDA approved therapy  
for Parkinson’s Disease***



# **Improving Quality of Life: Symptom-Specific Therapies**





# Hot Topic: The Parkinson's Gloves





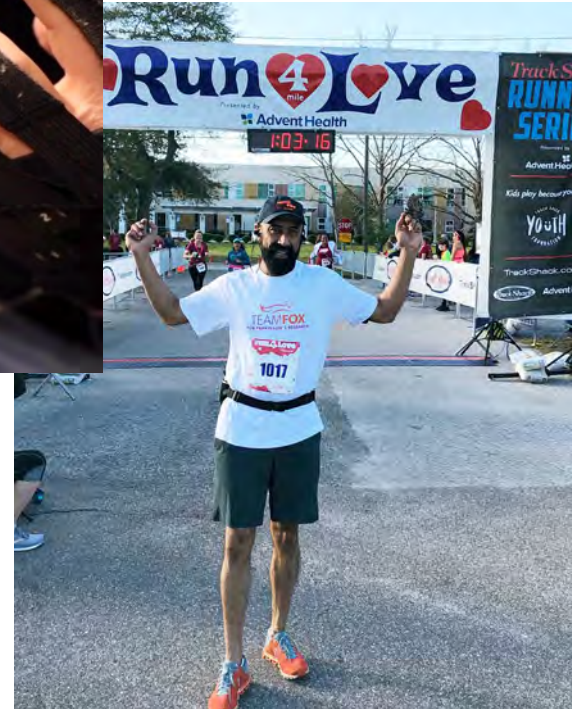


# The Parkinson's Gloves

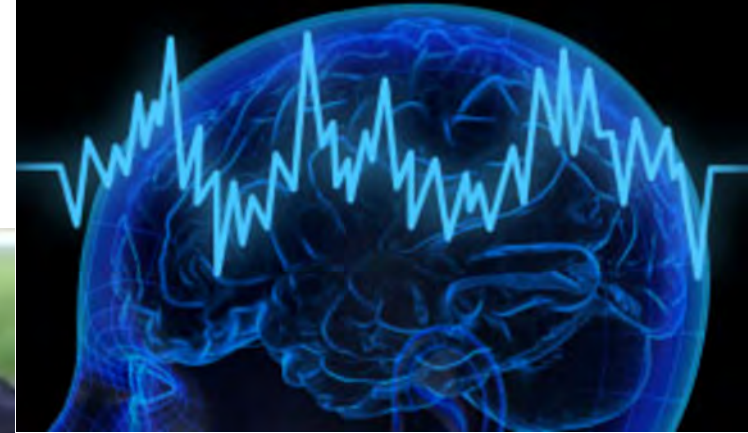
- Featured on Good Morning America
  - (December 2022)
- Stanford Medicine
  - Peter Tass Labs

Vibration in fingertips

- “**Resets**” electrical activity in the brain
- Tested for:
  - Swallowing
  - Tremor
  - Freezing of gait



# The Parkinson's Gloves




***Next Steps:  
Not yet recruiting.  
Website survey to sign  
up for future studies.***

***Similar glove study  
recruiting in  
Portland, Oregon***

# Good vibrations: tactile cueing for freezing of gait in Parkinson's disease



E. C. Klaver<sup>1,2</sup>  · J. P. P. van Vugt<sup>1</sup> · B. R. Bloem<sup>3</sup> · R. J. A. van Wezel<sup>2,5</sup> · J. Nonnekes<sup>4,6</sup> · M. C. Tjepkema-Cloostermans<sup>1,7</sup>

## Why not Parkinson's socks?

- 2023 Dutch Study
- 31 patients
  - 60-65% felt that wearing vibrating socks helped
  - Most used with an audio cue (eg, counting or metronome)

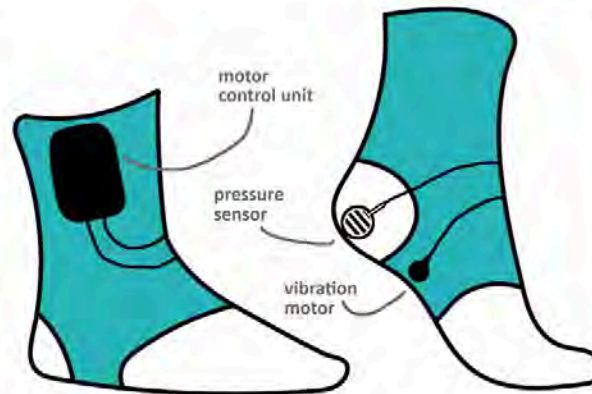


Fig.1 Schematic overview of the vibrating socks, including the motor control unit, pressure sensor (FlexiForce A401 pressure sensor) and vibration motor (Adafruit Mini Motor Disc 1201)

Journal of Neurology (2023) 270:3424–3432  
<https://doi.org/10.1007/s00415-023-11663-9>



# Hot Topic: Marijuana, CBD, and Parkinson's Disease



## Expert Briefing Webinar

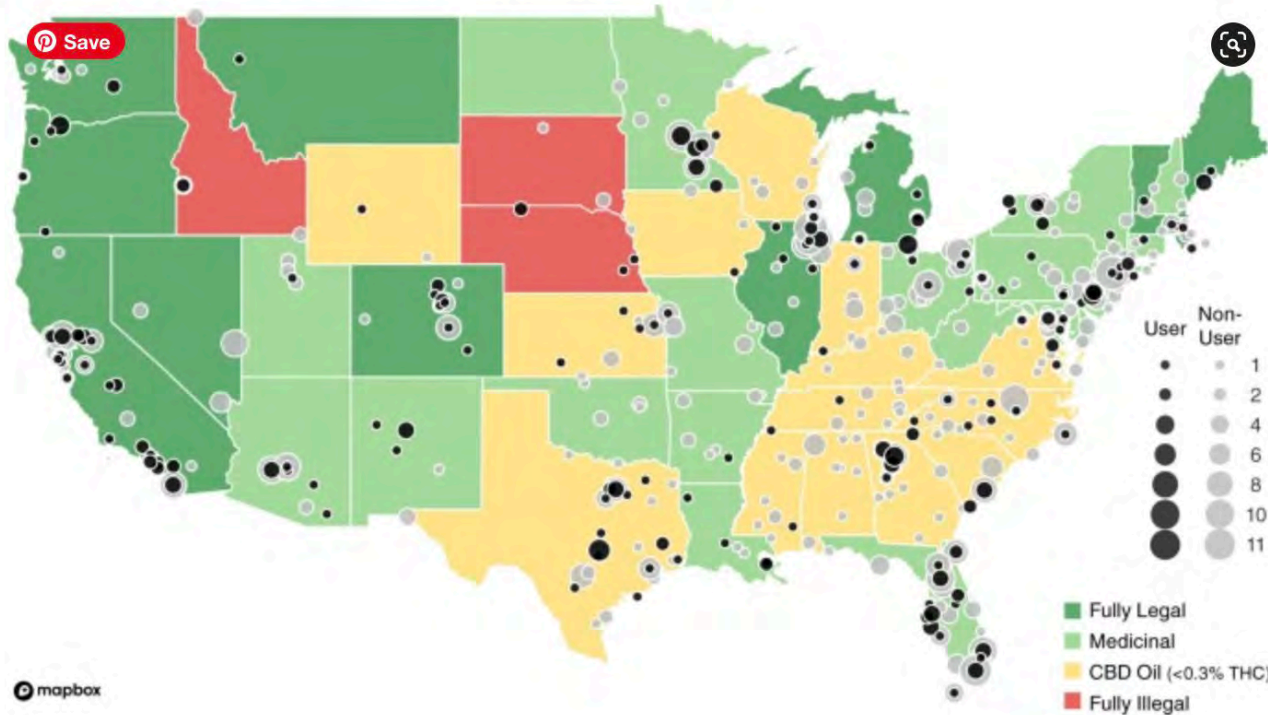
Marijuana & Parkinson's Disease:  
What do we Really Know?







Fig. 1: A Geographic representation of survey participants.



Feeney, M.P., Bega, D., Kluger, B.M. et al. Weeding through the haze: a survey on cannabis use among people living with Parkinson's disease in the US. *npj Parkinsons Dis.* 7, 21 (2021). <https://doi.org/10.1038/s41531-021-00165-y>



# Marijuana & PD

A few small studies (< 30 people)

- May help with:
  - Sleep
  - Tremor
  - Dyskinesias

Barriers:

- Hard to use same form
- Hard to use same doses
- Hard to "measure" improvement

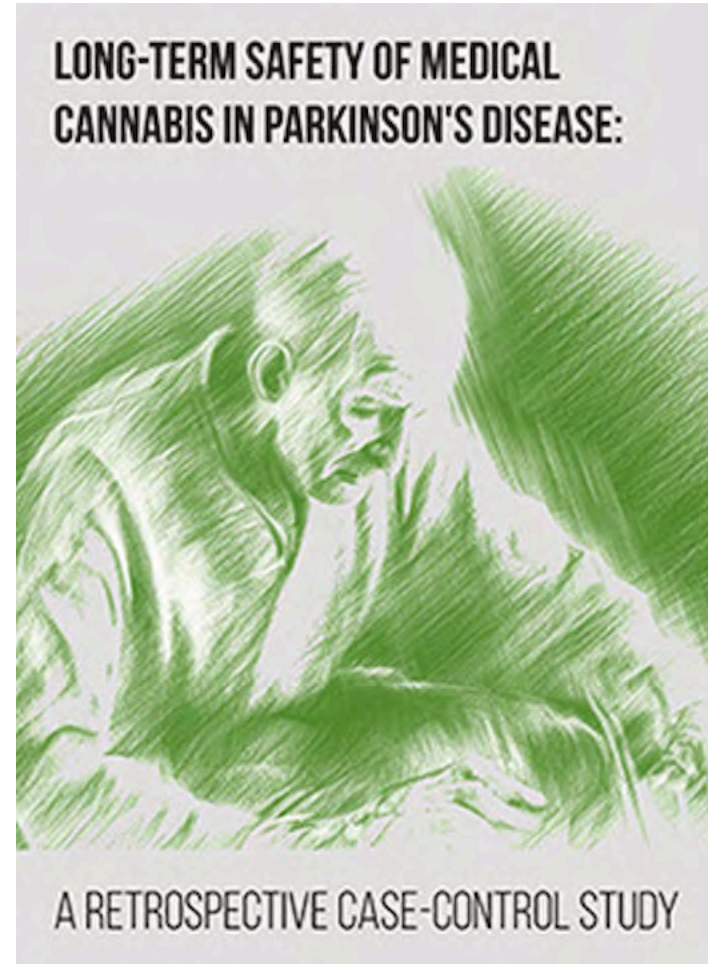
**Bottom Line:  
Not Enough Data**





# Marijuana & PD

- 2023 Parkinsonism & Related Disorders
  - 152 patients
    1. Treatment Group (Medical Cannabis)
    2. Control Group
  - Followed from 2008-2022



# Marijuana & PD



## RESULTS

### MOTOR OUTCOMES

LEDD H&Y



There were no significant differences between the MC and the control groups for LEDD or H&Y stage progression [ $p=0.90, 0.77$ , respectively].

### NON-MOTOR OUTCOMES



Based on self-reports by patients to their treating physicians, a Kaplan-Meier analysis revealed no evidence of relative worsening in psychotic, depressive, or cognitive symptoms over time in the MC-treated group [ $p=0.16-0.50$ ].

- **No effect** on motor symptoms or disease progression (good or bad)
- Did not worsen psychiatric or cognitive symptoms

# Marijuana & PD

## *Next Steps:*

- *Colorado Studies*
- *Trying different forms and doses*



## • *Looking at:*

- *Tremor*
- *Sleep*
- *Dream reenactment*
- *Hallucinations*
- *Memory*
- *Dyskinesias*
- *Anxiety*



# **Earlier Detection: Emerging Biomarkers**

# What is a Biomarker?



*“A measurable substance in an organism whose presence is indicative of some phenomenon such as disease, infection, or environmental exposure.”*



# How Can We Use Biomarkers?

*Clinical diagnosis still only has 80-90% accurate*

Biomarkers can be used to:

- **Detect** PD before it starts (“Prodromal”)
- **Confirm** or support your diagnosis
- **Guide** disease disease or prognosis
- **Differentiate** between clinically similar diseases
- **Identify** best candidates for clinical trials and specific therapies





# News-Worthy Biomarkers



**Breaking News:**  
**Parkinson's Disease**  
**Biomarker Found**

**Omaha**  
**World-Herald**

**CHI, Creighton researchers seek marker  
for Parkinson's blood test**



# Spinal Fluid Testing

Assessment of heterogeneity among participants in the Parkinson's Progression Markers Initiative cohort using  $\alpha$ -synuclein seed amplification: a cross-sectional study

*Andrew Siderow<sup>\*</sup>, Luis Concha-Marambio<sup>\*</sup>, David-Erick Lafontant, Carly M Farris, Yihua Ma, Paula A Urenia, Hieu Nguyen, Roy N Alcalay, Lana M Chahine, Tatiana Foroud, Douglas Galasko, Karl Kiebertz, Kalpana Merchant, Brit Mollenhauer, Kathleen L Poston, John Seibyl, Tanya Simuni, Caroline M Tanner, Daniel Weintraub, Aleksandar Videnovic, Seung Ho Choi, Ryan Kurth, Chelsea Caspell-Garcia, Christopher S Coffey, Mark Frasier, Luis MA Oliveira, Samantha J Hutten, Todd Sherer, Kenneth Marek, Claudio Soto, on behalf of the Parkinson's Progression Markers Initiative†*



Lancet (2022)

- Test detects **alpha synuclein** in the spinal fluid
- Requires a **spinal tap** (lumbar puncture)



# Spinal Fluid Testing

**87.7% of those with PD had a positive test**  
("Rule In PD")

**96.3% of Healthy Controls had a negative test**  
("Rule Out PD")

Even better for PD patients with change in sense of smell:

**Picked up 98.6% of cases**

**Downside:**

**Requires an invasive procedure**

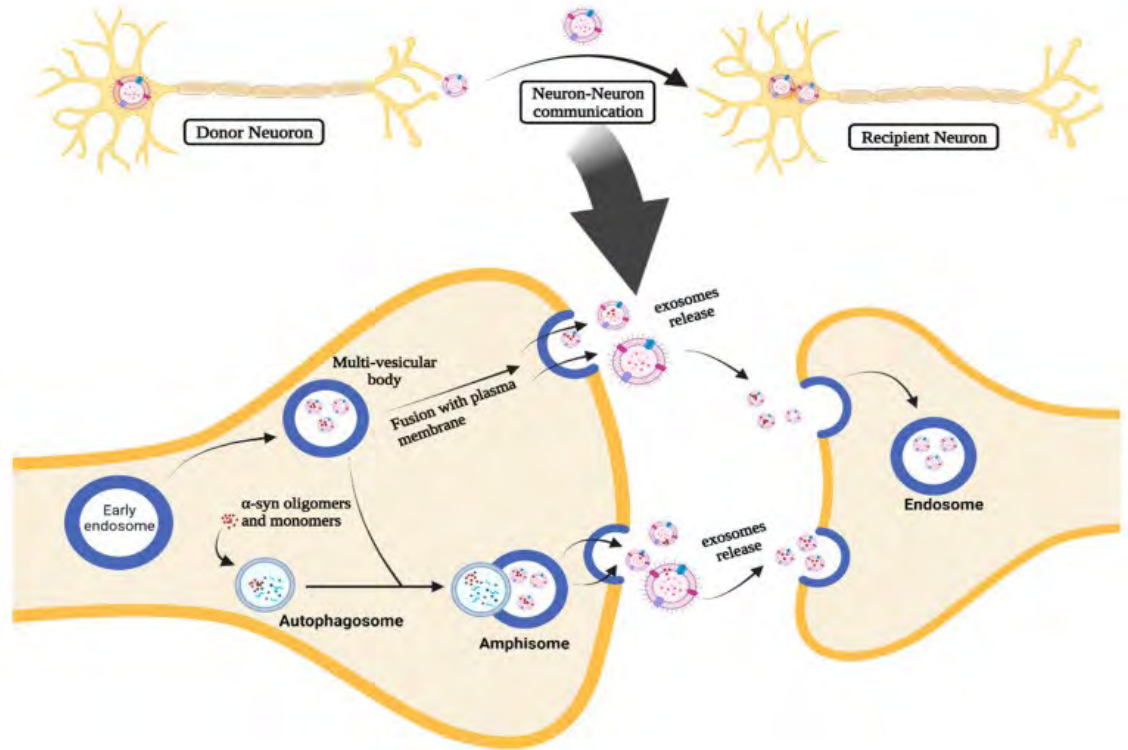


# CHI, Creighton researchers seek marker for Parkinson's blood test

Julie Anderson May 30, 2023 Updated May 31, 2023 0



Looking for a “messenger” in the blood that passes on bad alpha synuclein proteins



Compared blood tests from three groups:

1. Parkinson's
2. Healthy Controls
3. REM Behavior Disorder (RBD)

Considered a “precursor” for PD



# Plasma proteomics identify biomarkers predicting Parkinson's disease up to 7 years before symptom onset

Received: 6 April 2023

Accepted: 20 May 2024

Published online: 18 June 2024

Check for updates

Jenny Hällqvist<sup>1,2,13</sup>, Michael Bartl<sup>3,4,13</sup>, Mohammed Dakna<sup>3</sup>, Sebastian Schade<sup>5</sup>, Paolo Garagnani<sup>6</sup>, Maria-Giulia Bacalini<sup>7</sup>, Chiara Pirazzini<sup>6</sup>, Kailash Bhatia<sup>8</sup>, Sebastian Schreglmann<sup>8</sup>, Mary Xylaki<sup>3</sup>, Sandrina Weber<sup>3</sup>, Marielle Ernst<sup>9</sup>, Maria-Lucia Muntean<sup>5</sup>, Friederike Sixel-Döring<sup>5,10</sup>, Claudio Franceschi<sup>6</sup>, Ivan Doykov<sup>1</sup>, Justyna Spiewak<sup>1</sup>, Héroïse Vinette<sup>1,11</sup>, Claudia Trenkwalder<sup>5,12</sup>, Wendy E. Heywood<sup>1</sup>, Kevin Mills<sup>2,14</sup> & Brit Mollenhauer<sup>3,5,14</sup>

Computer model could predict who had PD

Blood tests looked similar in most RBD patients

Does this mean we can predict Parkinson's before symptoms start?





# Hot Topic: Artificial Intelligence (AI)







# AI and PD

## Potential Roles:

- Predict early signs and symptoms
- Assess disease progression and/or treatment response
- Close geographical barriers (allowing remote exams)

[J Parkinsons Dis.](#) 2021; 11(Suppl 1): S117–S122.

PMCID: PMC8385515

Published online 2021 Jul 16. Prepublished online 2021 Jun 28. doi: [10.3233/JPD-212545](https://doi.org/10.3233/JPD-212545)

PMID: [34219671](https://pubmed.ncbi.nlm.nih.gov/34219671/)

Will Artificial Intelligence Replace the Movement Disorders Specialist for Diagnosing and Managing Parkinson's Disease?

[Matt Landers](#),<sup>a,\*</sup> [Suchi Saria](#),<sup>b,c,d</sup> and [Alberto J. Espay](#)<sup>e,\*</sup>



# AI to Measure Disease Progression

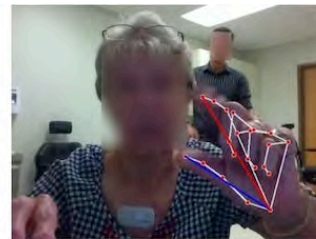
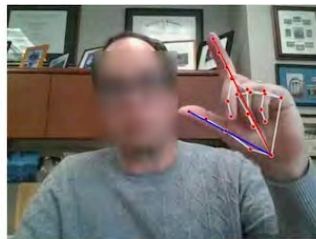
250 patients (PD & controls)

Performed **finger tapping** in front of a webcam

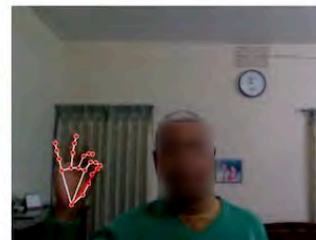
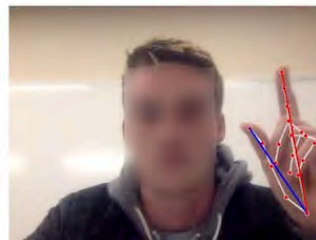
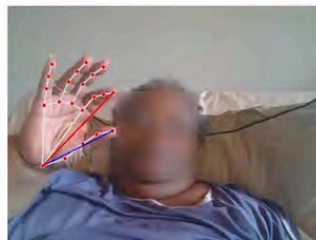
Compared:

- Expert neurologists
- Computer generated score

Individuals with PD



Healthy Control

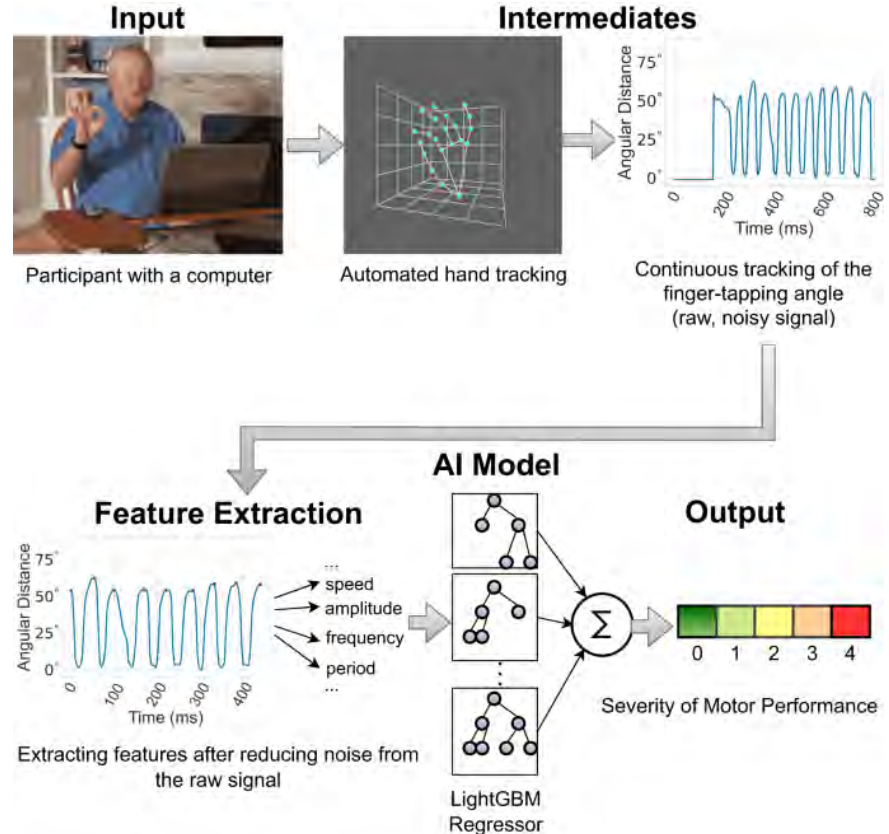




# AI to Measure Disease Progression

**Movement Disorder  
Neurologists were still  
the most accurate !!**

*AI outperformed non-  
Movement Disorder  
providers*





# Other Uses of AI

## Smartwatch & other wearable devices

- Track symptoms
- Cognitive exercises
- Remote motor exams

### In-Clinic Assessments

Perform MDS-UPDRS Part III

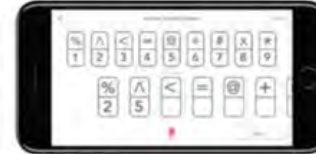


### Motor and Cognitive Tasks



### At-Home Assessments

Symptom Tracker, Cognitive and Psychomotor Tasks



### Instrumented Motor Exam





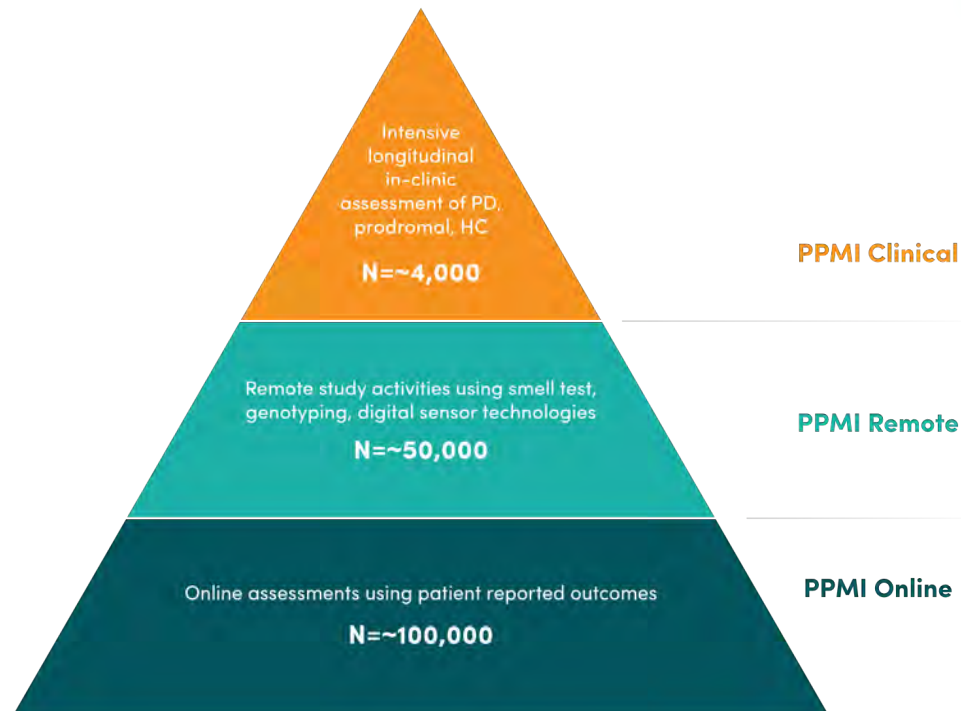
# Get Involved

# PPMI

- Michael J. Fox Foundation
- No PD diagnosis needed
- Fill out info online
  - Local: KC, Chicago, Denver
- Data accessible upon request



Parkinson's  
Progression  
Markers  
Initiative







# PD GENERation

- Michael J. Fox Foundation
- Need PD diagnosis
- In-person or remote options

1. Screening visit (15-30 min)
2. PD GENERation appointment (2 hours)
  1. Clinical assessments and cheek swab
3. Genetic counselor consultation (15-30 min)
  1. Receive and review test results



## **PD GENERation:**

Mapping the Future of  
Parkinson's Disease

Help us change the course of Parkinson's



# “How Do I Get Involved?”



Visit **clinicaltrials.gov**



Call or email the **UNMC Research Advocate Office**

[unmcrsa@unmc.edu](mailto:unmcrsa@unmc.edu)

402-559-6941



Reference the **UNMC Clinical Trial Database:**

[https://net.unmc.edu/ctsearch/index\\_unmc.php](https://net.unmc.edu/ctsearch/index_unmc.php)



# Useful Websites

- [www.pdtrialtracker.info](http://www.pdtrialtracker.info)
- [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
- [www.apdaparkinson.org](http://www.apdaparkinson.org)
- [www.michaeljfox.org](http://www.michaeljfox.org)
- World Health Organization (WHO) Registry



HDR © 2017 Dan Schwalm

UNIVERSITY OF  
**Nebraska**  
Medical Center







# Parkinson's Nebraska

*A Journey Shared.*

From the Founder of  
Parkinson Health  
Development, Colleen  
Wuebben (1952-2013)

# ORIGINATION



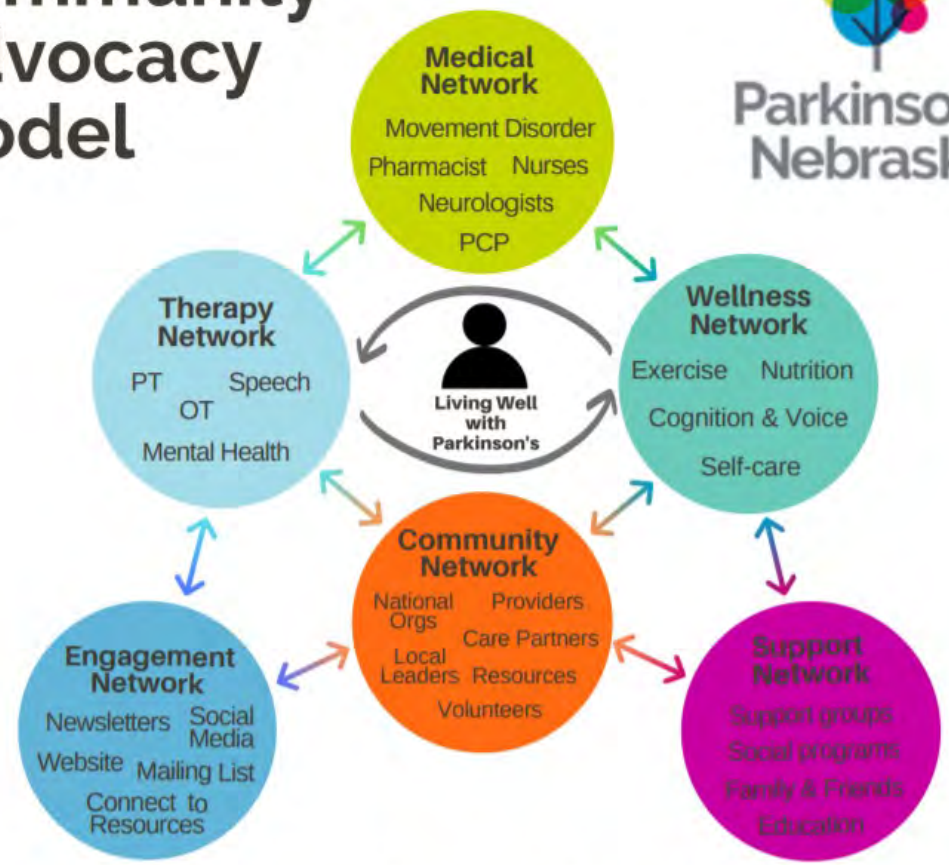


- Our mission is to educate all of the Nebraskan's living with Parkinson's Disease as well as their caregivers of the resources available to support them in their journey. We are committed growing and developing our organization in pursuit of serving as many people as possible in the state. The more we grow, the more we can give. We are passionate, we are local, and we are committed to our community.

## WHAT DRIVES US?

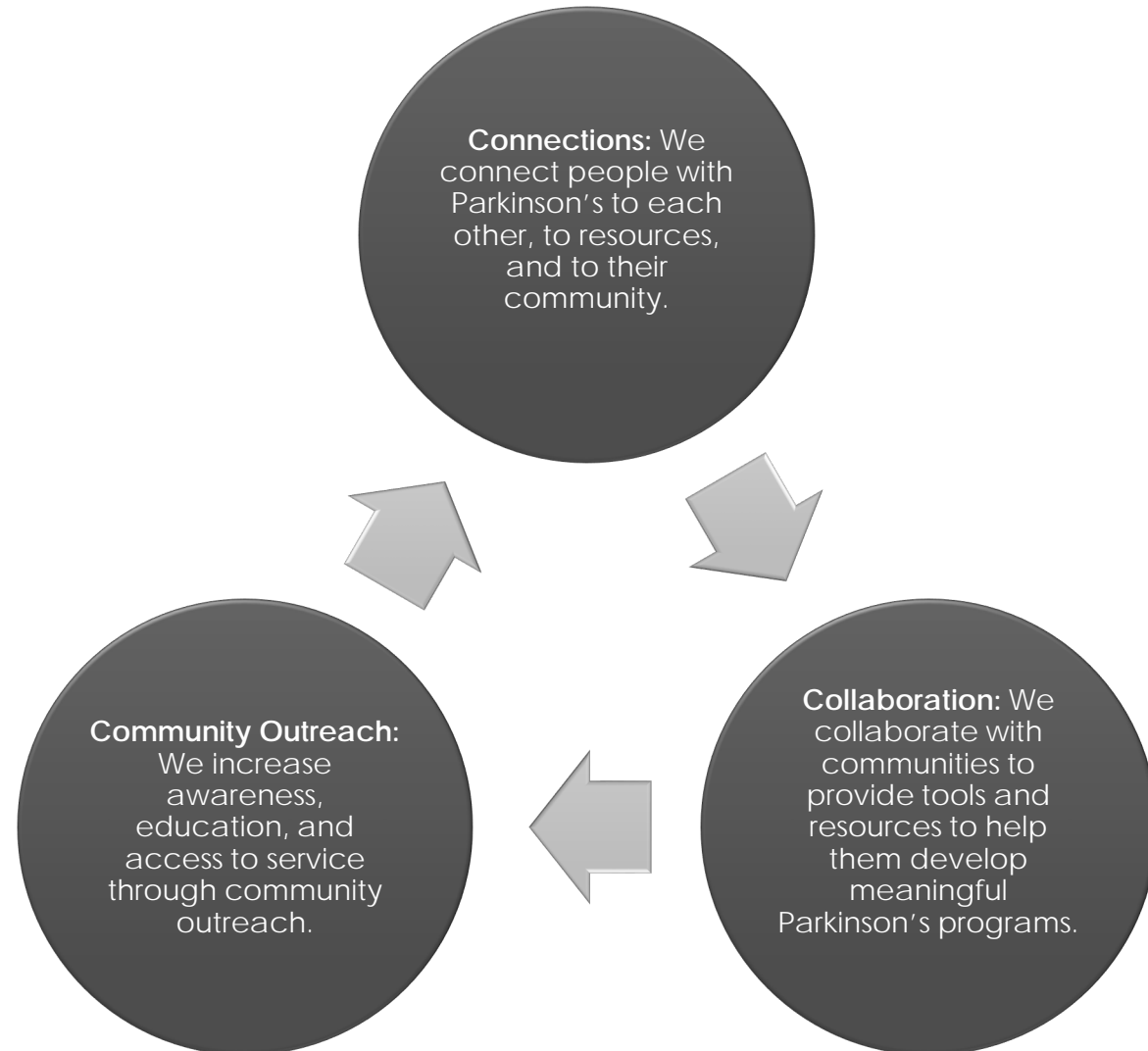


# Community Advocacy Model



[www.parkinsonsnebraska.org](http://www.parkinsonsnebraska.org)

# BUILDING STRONG COMMUNITIES



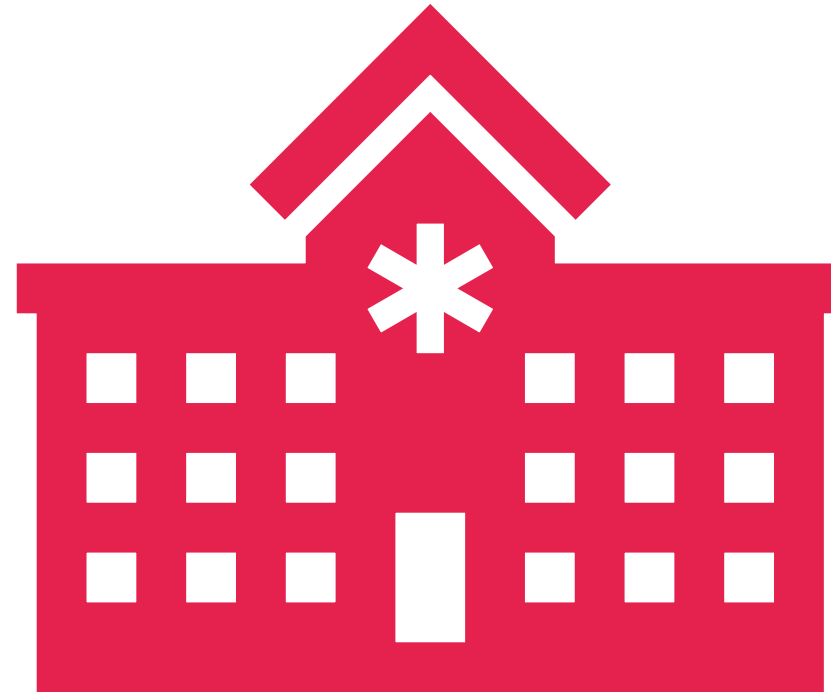
# OTHER WAYS WE SUPPORT THE COMMUNITY



# WHAT CAN WE PROVIDE?

Grants:

- Wellness
- Educational
- Support





# HOW CAN YOU HELP?

- Spread awareness
- Notify the community of our organization
- Donate or become a business sponsor
  - <https://parkinsonsnebraska.org/donate/>



Thank you to our  
2024 Business  
Sponsors!



# PARKINSON'S NEBRASKA



**16811 Burdette Street Suite 1**



**Upcoming Support Groups**

November 14<sup>th</sup>

December 12<sup>th</sup>





# Cognitive Changes in Parkinson's Disease (PD)

Pamela E May-Weeks, PhD, ABPP  
Clinical Neuropsychologist, Associate Professor  
Dept. of Neurological Sciences, UNMC





I have no financial disclosures.

Presentation is for informational purposes only, **not** for diagnosis or treatment

The background of the slide is a close-up, high-resolution image of a fingerprint. The ridges and valleys of the fingerprint are rendered in shades of teal, blue, and green, creating a complex, textured pattern. In the upper right corner, there is a solid, bright red rectangular block. The text "What is Cognition?" is centered in the lower half of the image.

*What is Cognition?*



# What is Cognition?

- Mental speed
- Attention
- Learning
- Memory (recall and recognition)
- Language (e.g., naming, fluency, writing, repetition, comprehension)
- Visuospatial skills (e.g., perception of space, assembly, navigation)
- Executive functions (e.g., planning, organizing, set-shifting, problem-solving, inhibition)
- General intellect



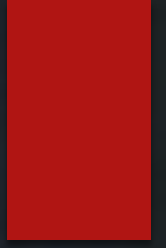
# What Affects Cognition?

- Age
- Psychiatric symptoms
- Sleep, fatigue
- Nutritional status, vitamin deficiencies
- Pain
- Vision, hearing
- Infections
- Thyroid functions
- Blood sugar levels
- Medication side effects

*...among other factors*



# *PD Basics*

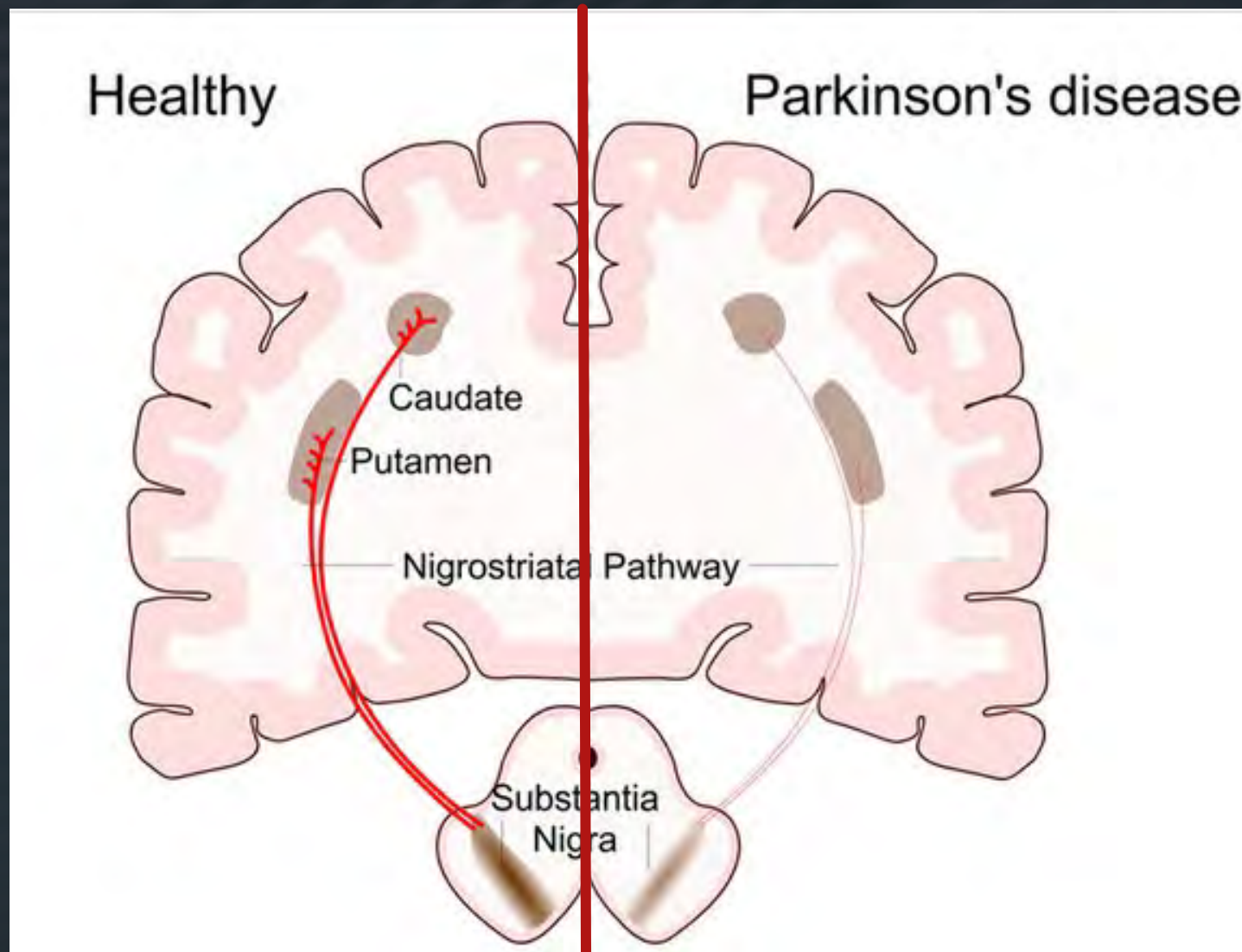




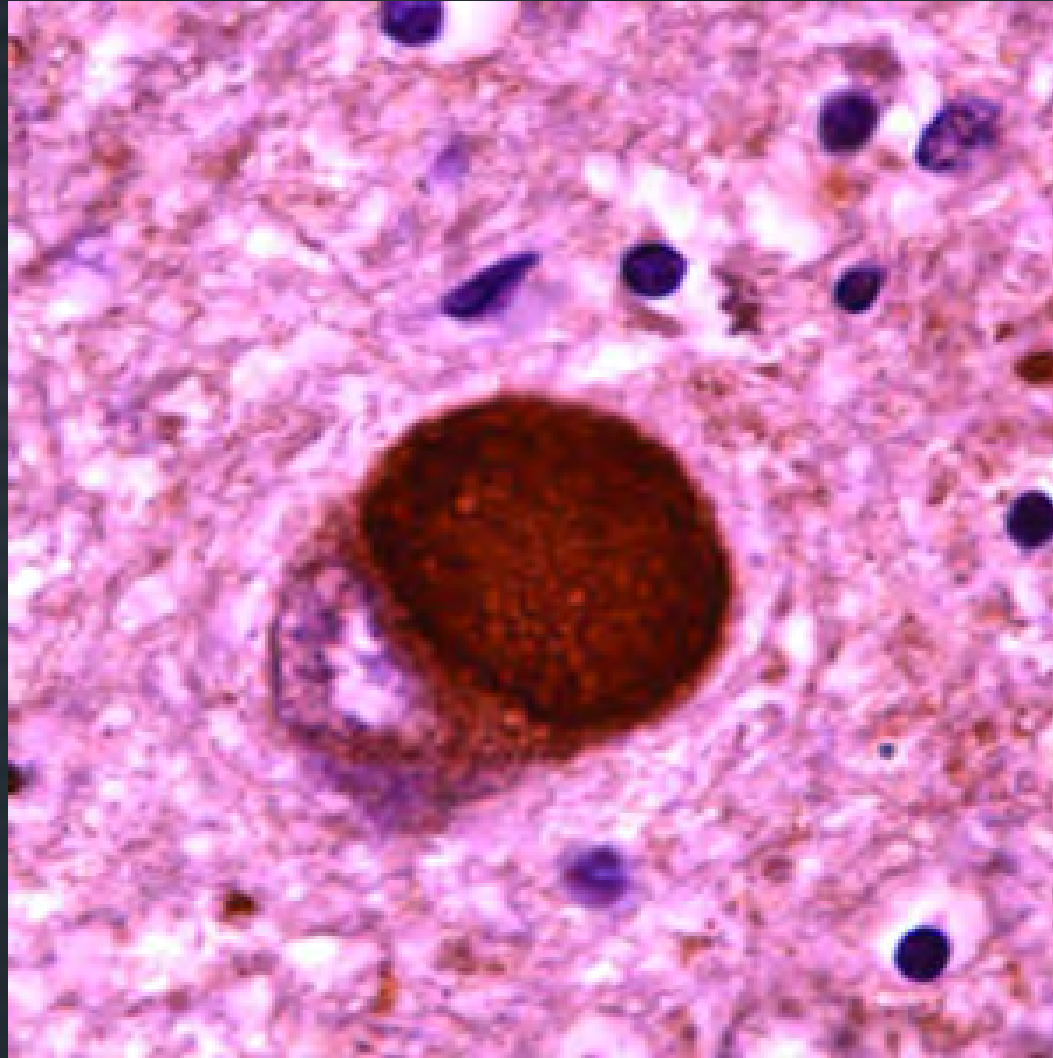
# PD Basics

- 2<sup>nd</sup> most common age-related neurodegenerative disorder after Alzheimer's disease
- Prevalence: 100-200 per 100,000 adults over age 40 in North America and Europe. Nearly 1 million people have PD in U.S.
- Incidence increases rapidly after age 60
- Mean age at diagnosis is 70.5 years old
- Men are more likely to have PD than women

# PD Basics

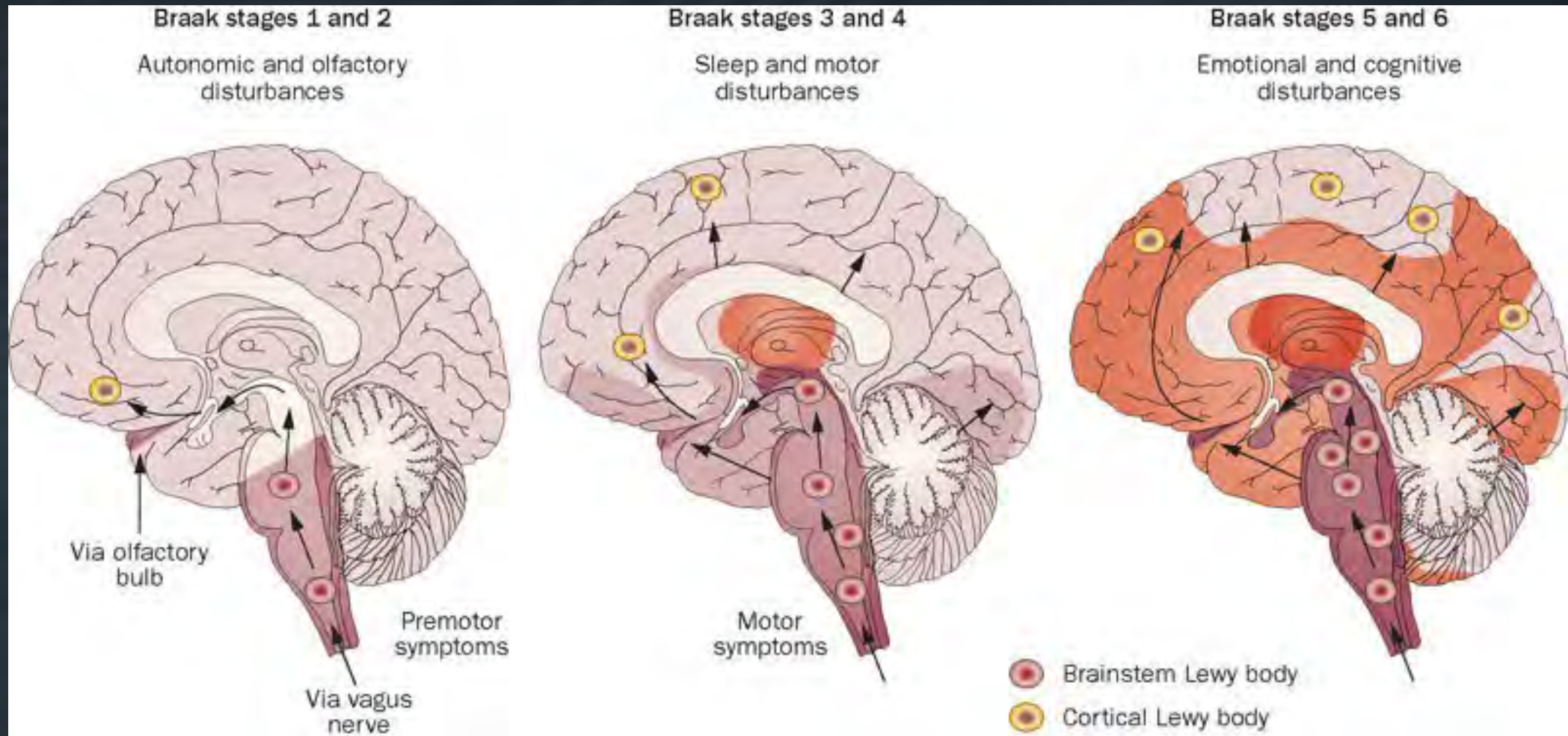


# PD Basics





# PD Basics

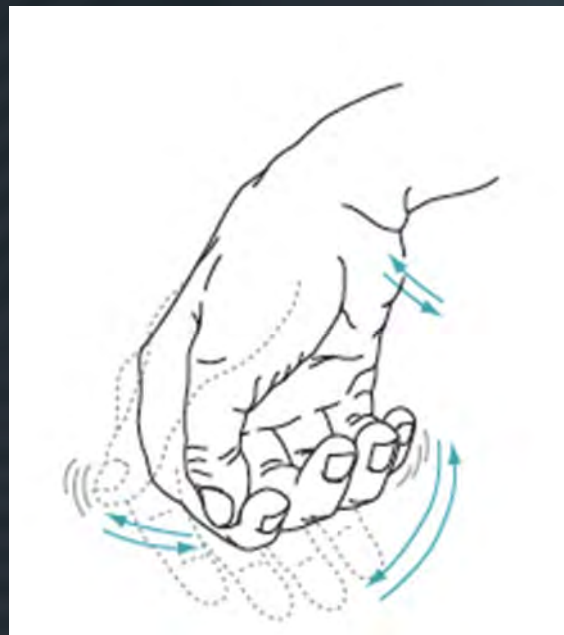


# PD Basics:

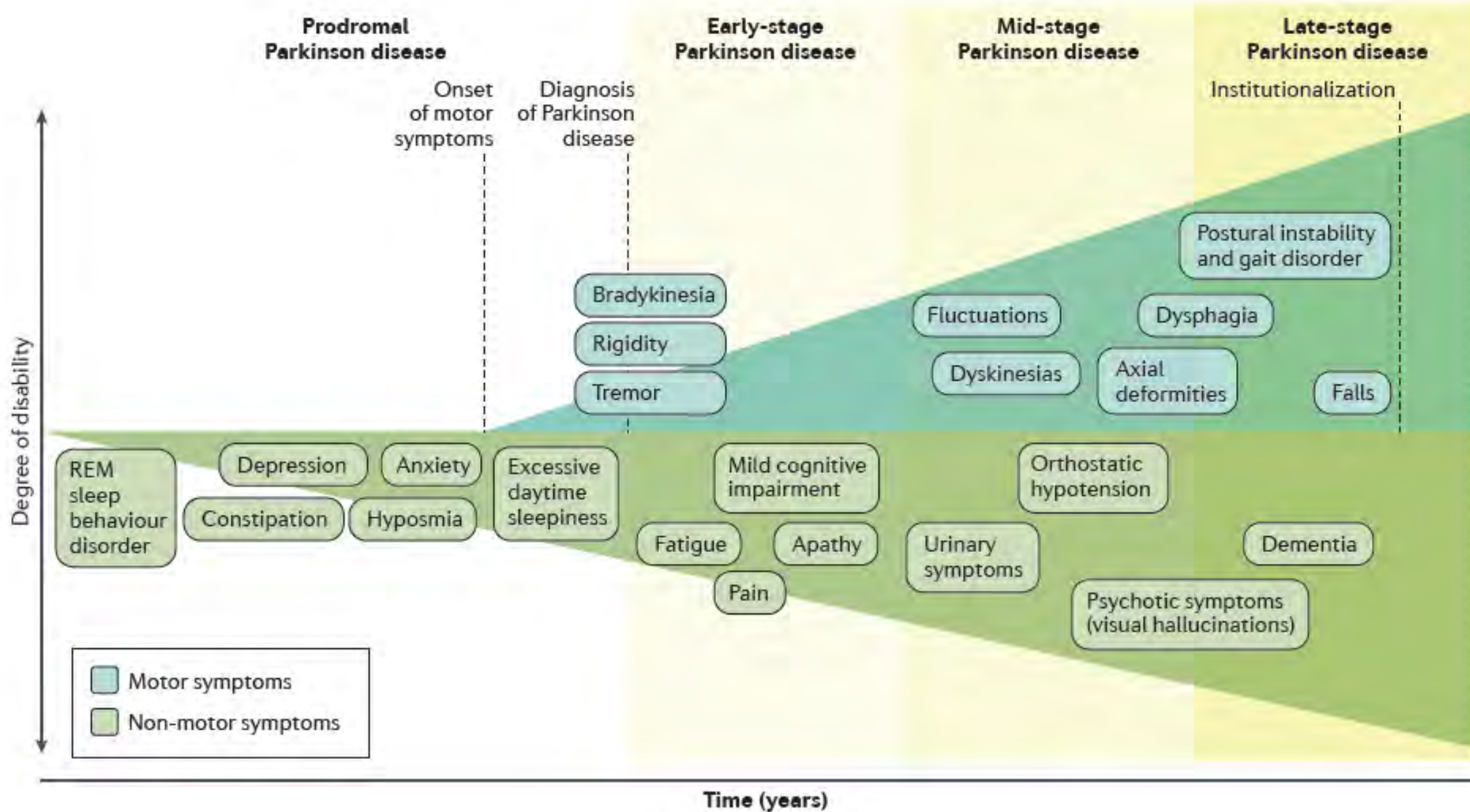
## *Motor Features*

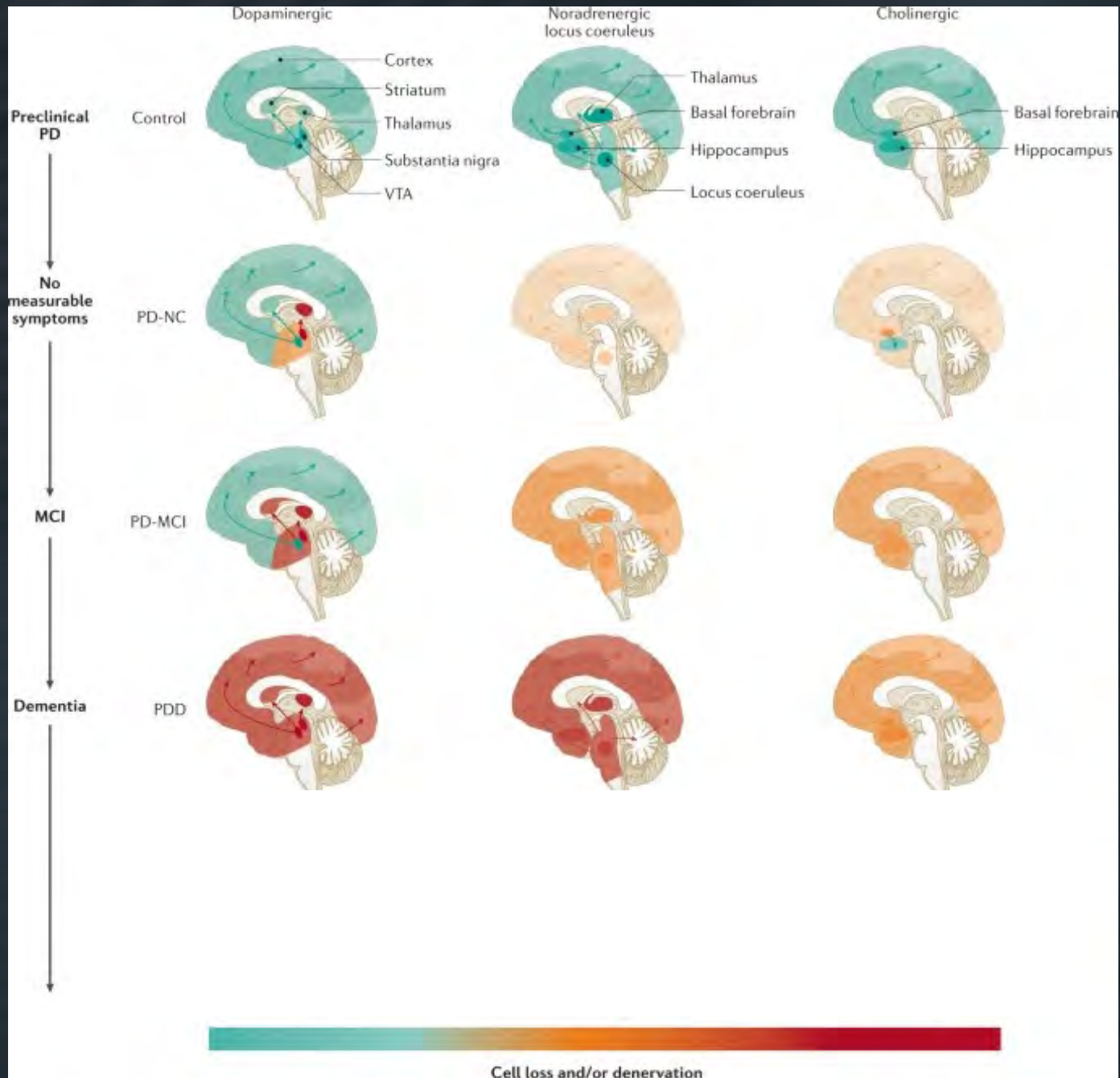
Four cardinal symptoms (TRAP):

- Tremor (resting)
- Rigidity
- Akinesia/bradykinesia
- Postural instability

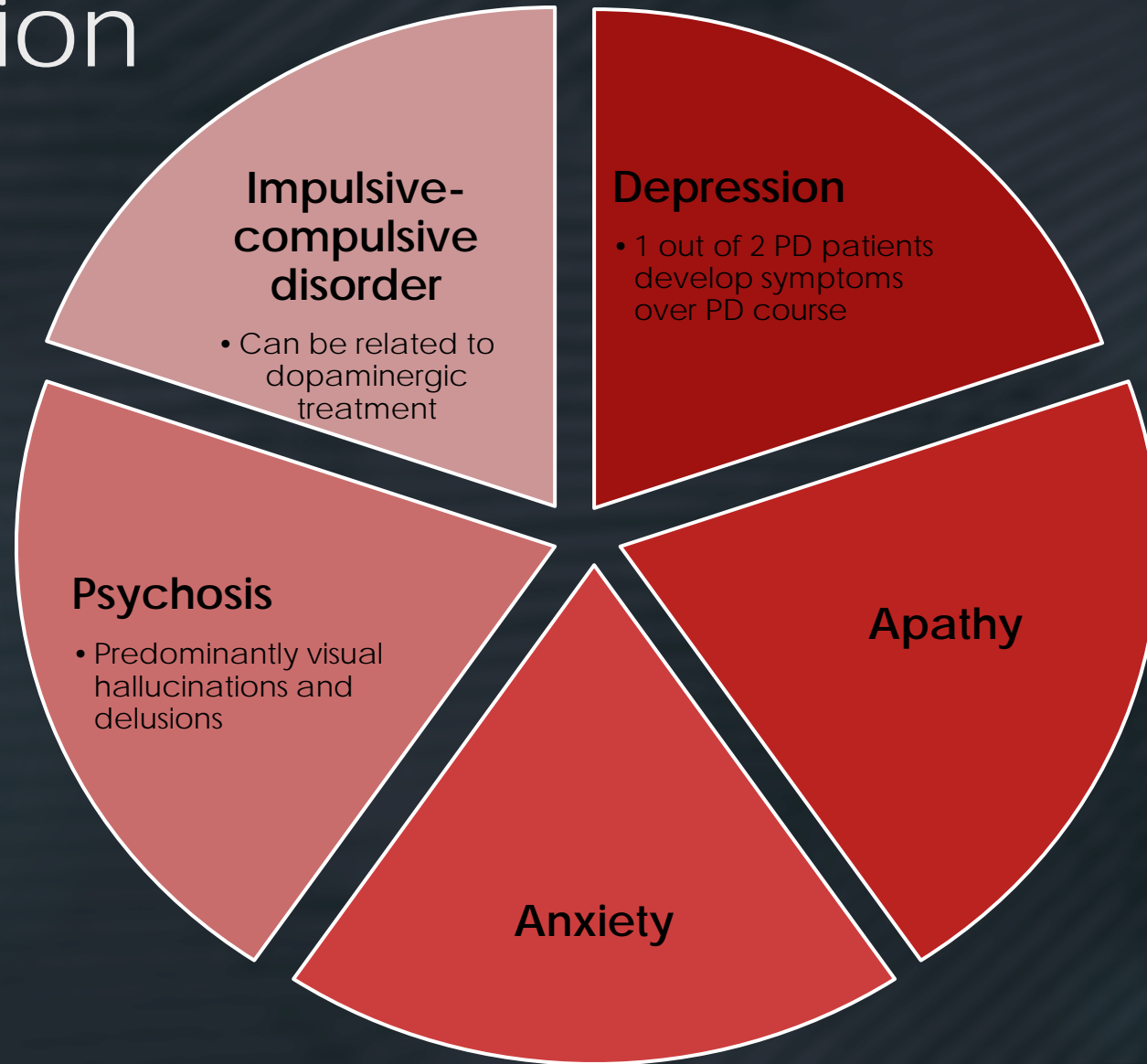








# PD as a *Neuropsychiatric* Presentation





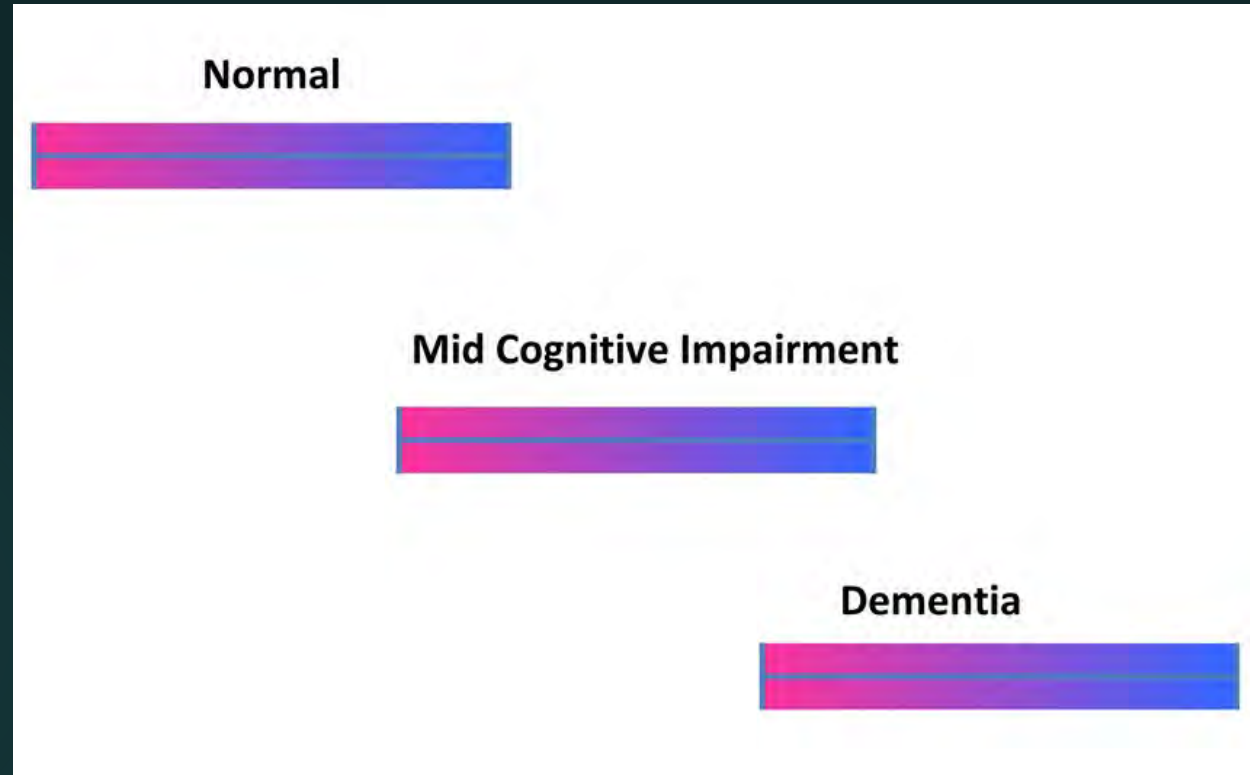


# *Cognitive Trajectories*

# Classification Continuum

## Mild Cognitive Impairment:

- 1) Modest decline from a previous level of cognitive performance
- 2) The cognitive deficits do not significantly interfere with independence in everyday activities



## Dementia:

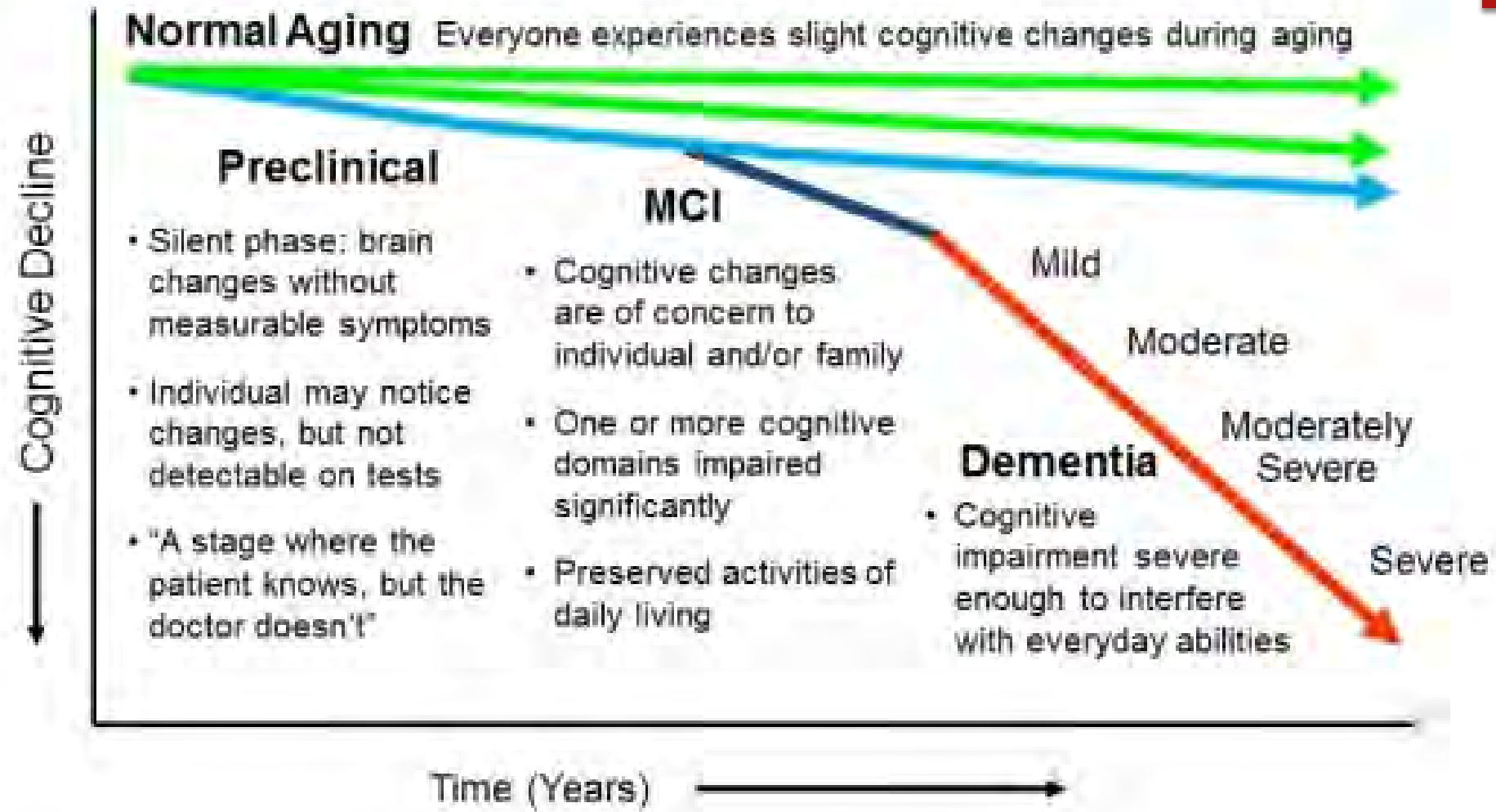
- 1) Significant cognitive decline from a previous level of cognitive functioning
- 2) The cognitive deficits interfere with independence in everyday activities
- 3) A behavioral symptom(s) may be apparent (apathy, depressed or anxious mood, hallucinations, delusions)

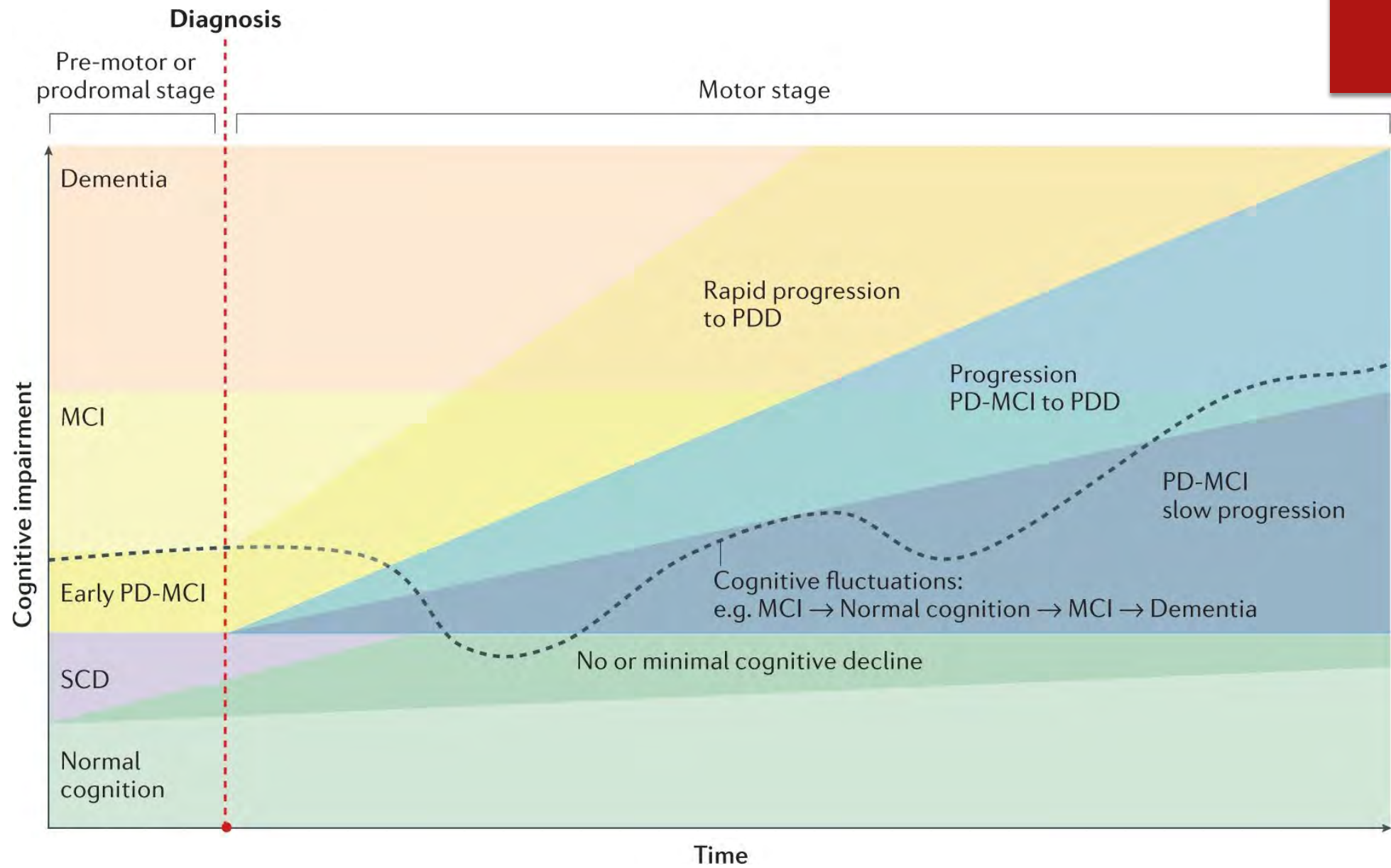


# TYPES OF DEMENTIA

Dementia is an umbrella term for loss of memory and other thinking abilities severe enough to interfere with daily life.

- 👉 **Alzheimer's** 60-80% of cases
- 👉 **Vascular** 15-25% of cases
- 👉 **Lewy body** 5-10% of cases
- 👉 **Frontotemporal** 5-6% of cases
- 👉 **Other, including Huntington's** For PD, 3-4% of cases
- ★ **Mixed dementia:** Dementia from more than one cause







# Prodromal PD

Phase during which signs, symptoms, genotype, or biomarker findings suggest presence of early neurodegeneration, but the patient does not fully exhibit motor features for PD diagnosis

3 prodromal clinical markers associated with highest likelihood of future PD are:

- REM sleep behavior disorder (RBD)
- Olfactory loss
- Reduced dopamine transporter (DAT) binding

Cognitive weaknesses have been associated with all of these

# Cognitive Changes

*Early in PD course, subtle changes in:*

- Retrieval memory and planning, organizing, and other executive functions

*With mild cognitive impairment, difficulties may arise in:*

- Attention: sustaining attention, shifting attention, completing multi-step processes
- Executive functions, including inhibition and regulation
- Mental speed (increased time to register, retrieve, and respond to information)
- Language (word-finding)
- Retrieval of recent memories (yet benefiting from cues, reminders)
- Visual perception

*With dementia, additional difficulties may arise in:*

- Comprehension
- Naming
- Memory (benefiting less from cueing, reminders)

# Recognizing Emotions

More difficult for people with PD to identify others' emotions

- Particular difficulties with identifying or making sense of negative emotions, such as anger, disgust, fear, and sadness, of others' facial expressions and voices

People with PD may have difficulties identifying their own emotions

- Otherwise known as "alexithymia"
- Independent of depression
- People with PD and cognitive decline may not be aware that they are depressed



# General Risk Factors Associated with Developing PD Dementia

## *Demographic factors:*

- Older age
- Male sex
- Later age of PD onset

## *Potentially modifiable factors:*

- Depression
- Head injuries
- Tobacco use
- Hypertension

## *Disease variables:*

- Olfactory dysfunction
- Visual hallucinations
- REM sleep behavior disorder (RBD)
- Non-tremor/akinetic rigid predominant PD
- ApoE4
- Longer duration of PD symptoms
- Mild Cognitive Impairment

# General Risk Factors Associated with Developing PD Dementia

Proportion of people with PD and dementia is about 30%

People with PD have a six-fold increased risk of developing dementia versus people without PD



# Protective Factors Against Developing PD Dementia

Years of education / higher education

And likely, exercise, diet, sleep, limiting substance use, and managing other chronic illnesses adequately

# Cognitive Features of Dementias

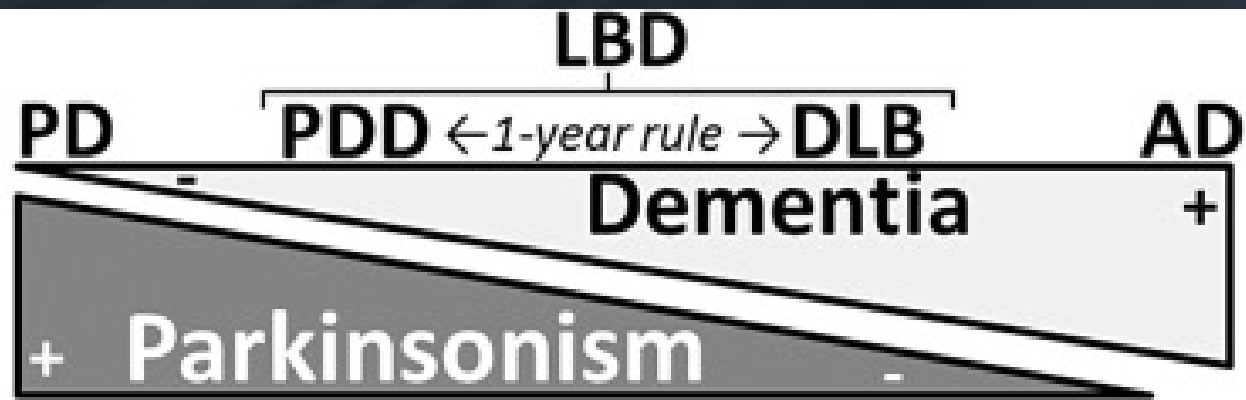
Dementia of Alzheimer's type (AD): Key impairment is memory, followed by language and orientation

Dementia with Lewy bodies (DLB): Key impairments in attention, executive functions, visuospatial abilities, and episodic memory, with some language involvement

- People with DLB tend to decline more rapidly than people with AD in the visuospatial domain


Parkinson's disease dementia (PDD): Key impairment in executive function. Also tend to have reduced attention, slowed processing speed, and alterations in visuospatial functioning

- People with PDD tend to decline at a slower rate on language measures than people with DLB or AD



	PD	PDD	DLB	AD
<b>Cognitive deficits</b>	Rare and mild	Late	Early and typical	
- Dementia	None	Late	Typical	
- Memory and attention	None	Variable	Prominent	
- Hallucinations and delirium	Rare	Typical	Occasional	
- Delusions	Occasional	Typical		
- REM sleep disorder	Occasional	Typical	Rare	
- Depression	Common			
<b>Parkinsonism</b>	First manifestation		Late or none	Rare
- Rigidity	Typical		Rare	
- Bradykinesia	Typical		Rare	
- Gait and postural disturbances	Typical		Rare	
- Tremor	Typical	Variable	Rare	






# *Neurocognitive Diagnosis*




# What to Do?


- Talk to your doctor. Can be helpful to bring a loved one to this visit to discuss their observations
- Cognitive screen in office
- Comprehensive neuropsychological evaluation

# What is a Neuropsychological Evaluation?


 Record review and test selection based on history / referral question

 Interview

 Gather additional information from collaterals, outside medical records

 Cognitive and psychological testing / scoring

 Written report

 Feedback to patient of results, diagnosis, and recommendations



# *Recommendations*



# Modifications to Complex Tasks

- Work accommodations
- Driving evaluation by occupational therapist
- Medication management
- Financial oversight
- Communication habits
- Discuss surrogate decision maker



# Cognitive Compensatory Strategies

- Develop a routine and good habits, to make procedures “muscle memory”
- Use calendars, reminders on smartphone, and other visual and auditory cues for memory and planning
- Inform others when providing information too quickly or when something needs to be repeated. Ask others to write information down.
- Reduce distractions when possible (e.g., turn off the television or radio while you’re having a conversation)
- Avoid shifting back and forth between tasks
- Divide tasks into individual steps that are easier to complete
- Keep rooms well-lit to reduce issues with visual misperception

# Stay Engaged!

- Exercise to the extent it is safe
- Stimulate the mind with novel, cognitive activities (attend a lecture, read a book, learn a new hobby)
- Be social. Stay connected to friends and family

# Healthy Habits

- Diet (e.g., Mediterranean diet, adequate fluid intake)
- Sleep
- Avoiding toxins to the brain



# Medications

- Consideration of whether there are any offending medications that might contribute
- Optimizing “on” time, reducing “off” time
- Treating providers may offer medications for people with memory impairment



# Online Resources

- <https://www.parkinson.org>
- <https://www.michaeljfox.org>
- <https://davisphinneyfoundation.org/>
- <https://www.nia.nih.gov/health/brain-health/>
- <https://www.apdaparkinson.org>



Thank you for your  
attention



# **Deep Brain Stimulation for Parkinson's Disease**

**Josue Avecillas-Chasin MD, PhD**

**Stereotactic and Functional Neurosurgeon**

**Assistant Professor of the Department of Neurosurgery**

**University of Nebraska Medical Center**

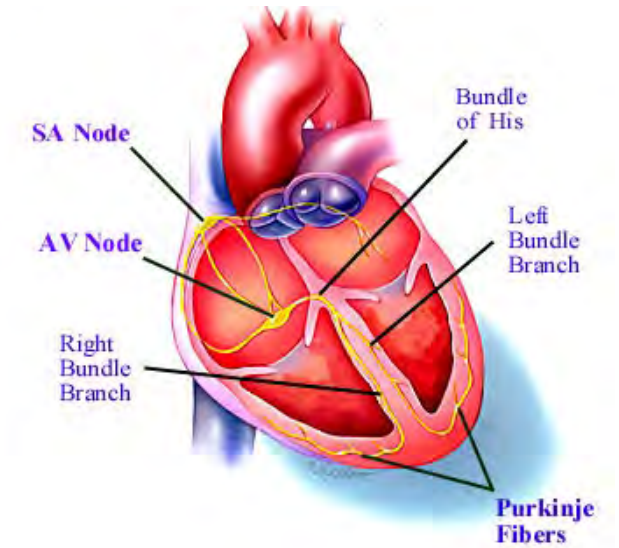
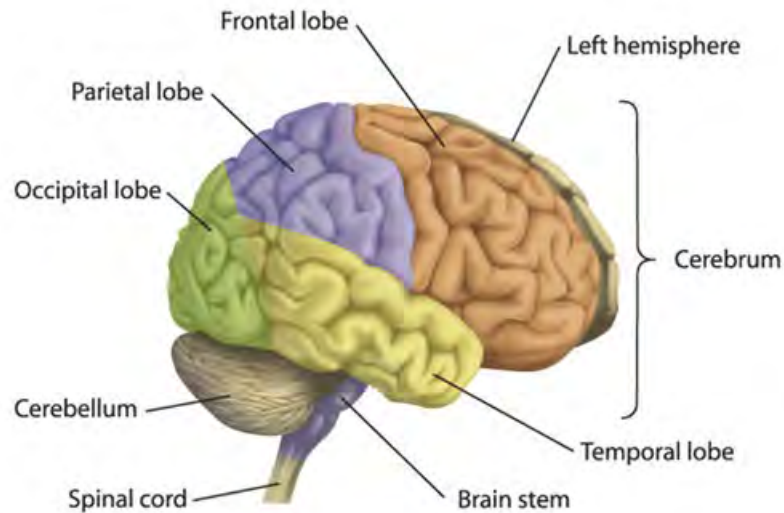




# What is DBS?





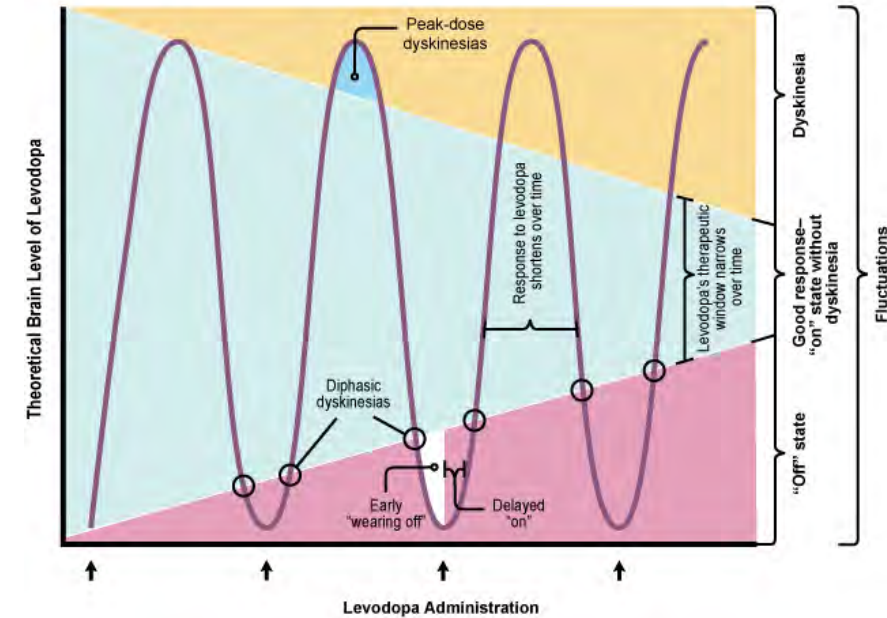


The Brain, much like the Heart is an **electrical organ**

Deep Brain Stimulation (DBS) >> *Brain Pacemaker*

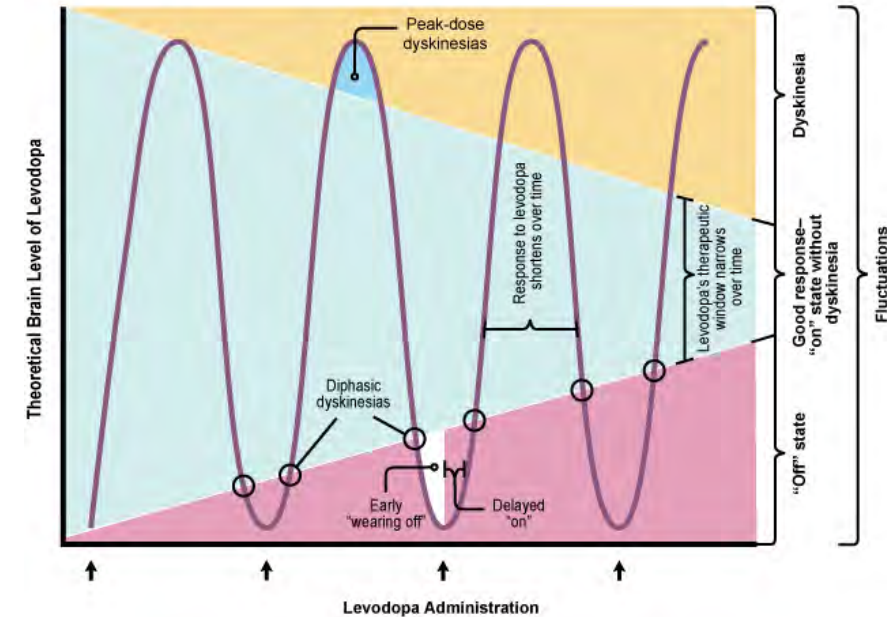
# When to Consider DBS

- Too much “off” time...“up and downs”



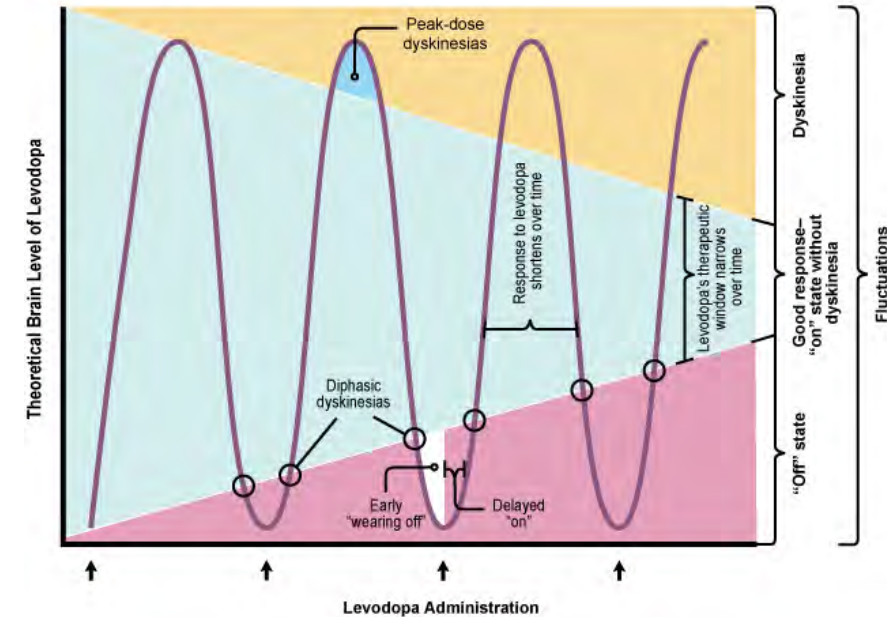
# When to Consider DBS

- Too much “off” time...“up and downs”
- Intolerable side-effects



# When to Consider DBS

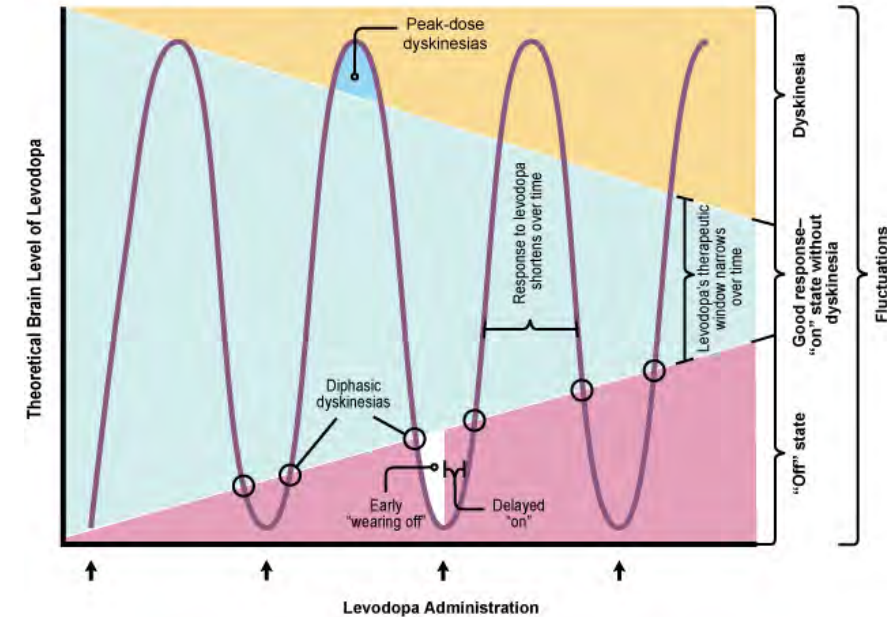
- Too much “off” time...“up and downs”
- Intolerable side-effects
- Insufficient tremor control
- Troublesome dyskinesias





# When to Consider DBS

- Too much “off” time...“up and downs”
- Intolerable side-effects
- Insufficient tremor control
- Troublesome dyskinesias
- Thinking about stopping hobbies/job





# How we define candidacy?: Team

- Neurologists
- Neurosurgeons
- Neuroradiologists
- Neuropsychologists
- Advanced practice providers
- Anesthesiologists
- Neurophysiologists
- Psychiatrists





# How we define candidacy?: Workup

- History & Neurological examination
- Levodopa responsiveness ON/OFF
- UPDRS Scales
- Imaging
- **Diagnosis**
- **Co-morbidities: Psychiatric**
- Quality of life: work and personal life
- Conservative treatments tried
- **Neuropsychological** evaluation

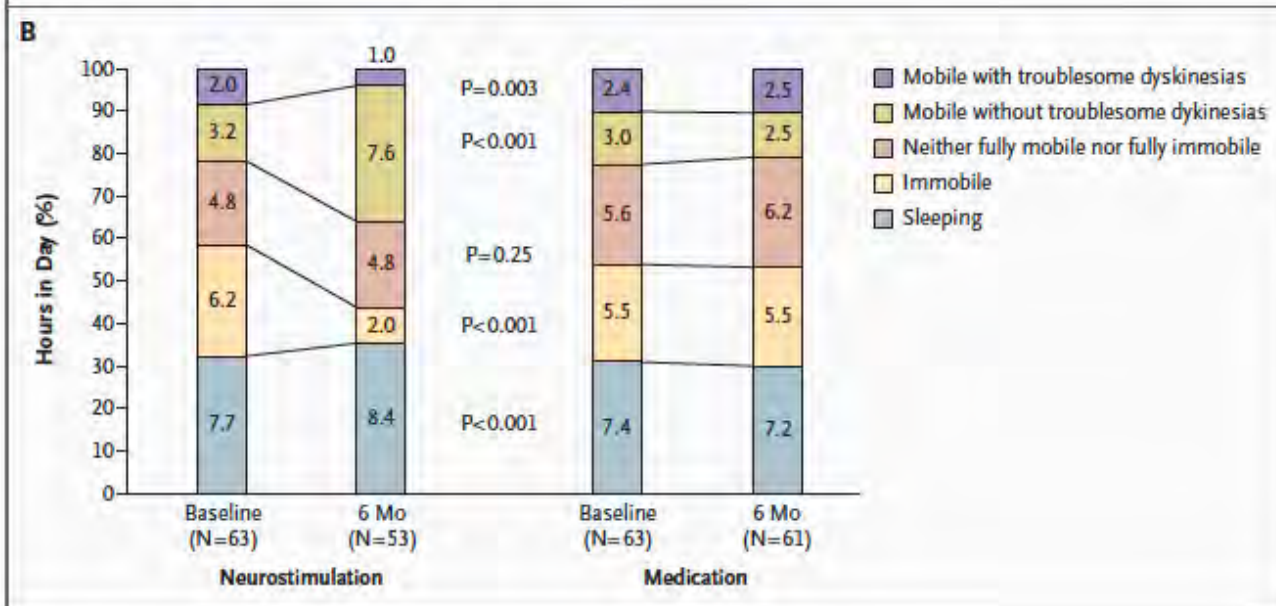
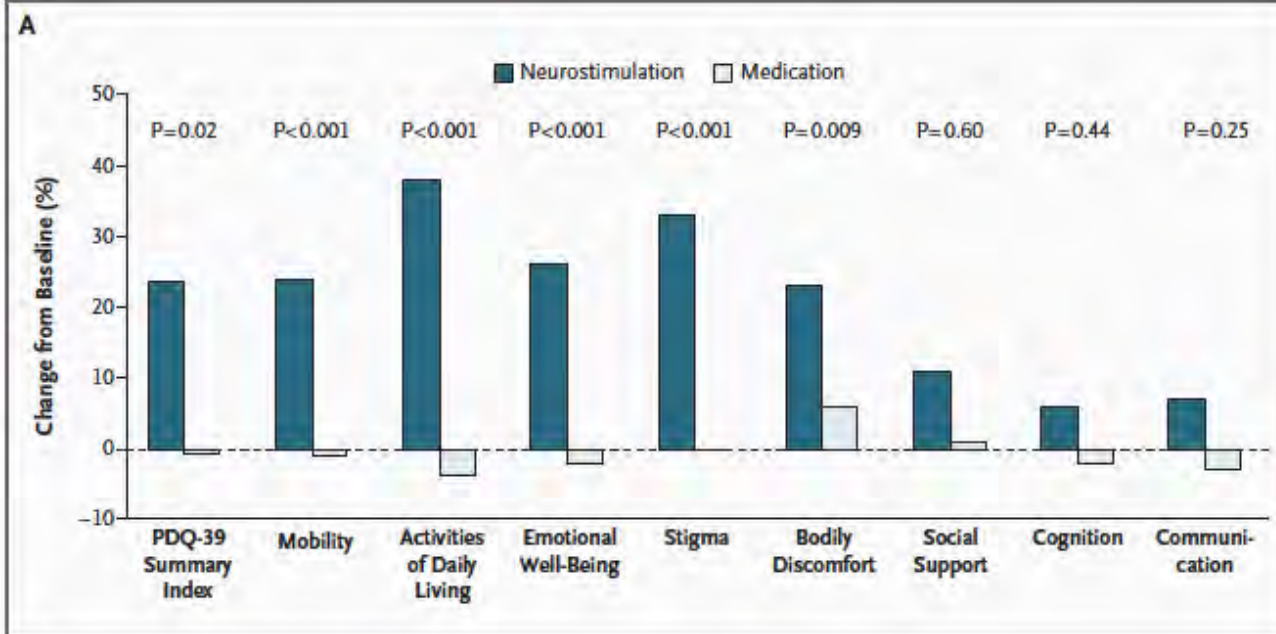




# Clinical Results of DBS







The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

## A Randomized Trial of Deep-Brain Stimulation for Parkinson's Disease

Günther Deuschl, M.D., Ph.D., Carmen Schade-Brittinger,



## **DBS is surgery of Last Resort?**







It's **not** about getting patients out of the nursing home, **it's about getting patients back on the golf course...**







*.....I waited too long....*

It's **not** about getting patients out of the nursing home, **it's about getting patients back on the golf course...**



# Parkinson's disease





# Parkinson's disease





# Goals of DBS

- To **Improve** quality of life >> **symptomatic treatment**
- Not Cure
- **Hope** for medically intractable patients







# Expectations

- **70%** reduction in dyskinesias
    - 50% medication reduction
  - **80%** reduction in resting tremor (Essential tremor)
  - **60%** reduction in bradykinesia
  - **70%** reduction in rigidity
  - **60-70%** reduction in dystonia
- 
- **70%** improvement in peak ON-time
  - **70%** reduction in worst OFF-time





# Expectations

- Freezing of gait (especially ON-freezing)
- Axial Instability
- Balance issues (Tend to avoid STN)
- Cognitive issues (?)
- Apathy (?) (Better with STN)
- Depression and anxiety (?)

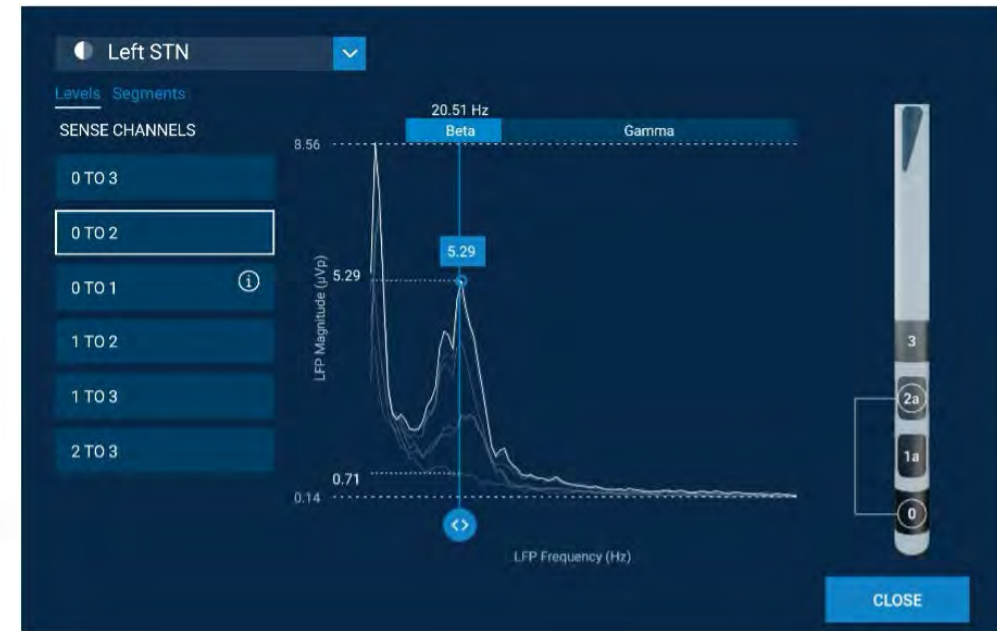




# Before surgery

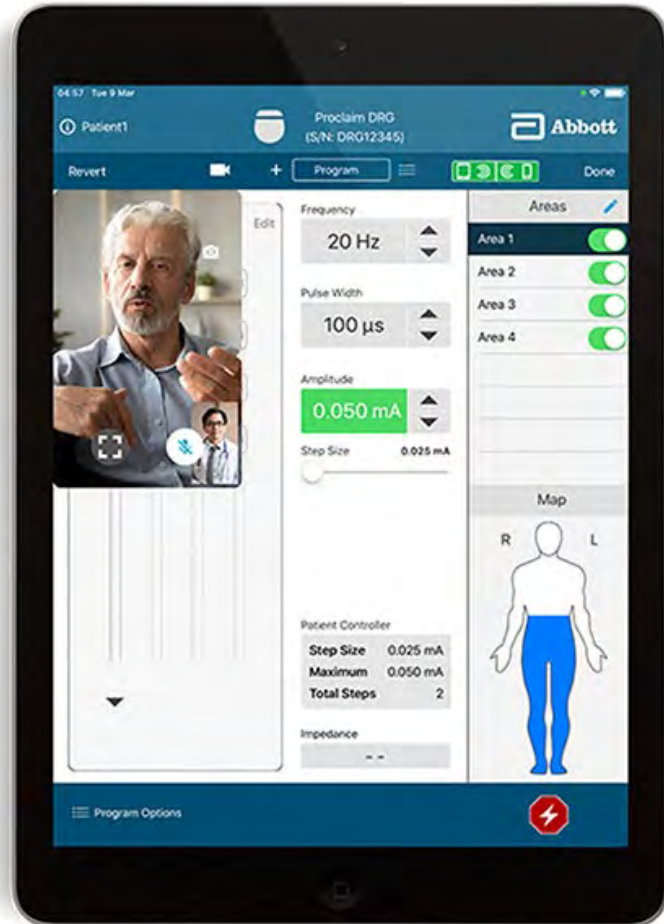


# The Device: Medtronic





# The Device: Abbott



# The Device: Boston Scientific



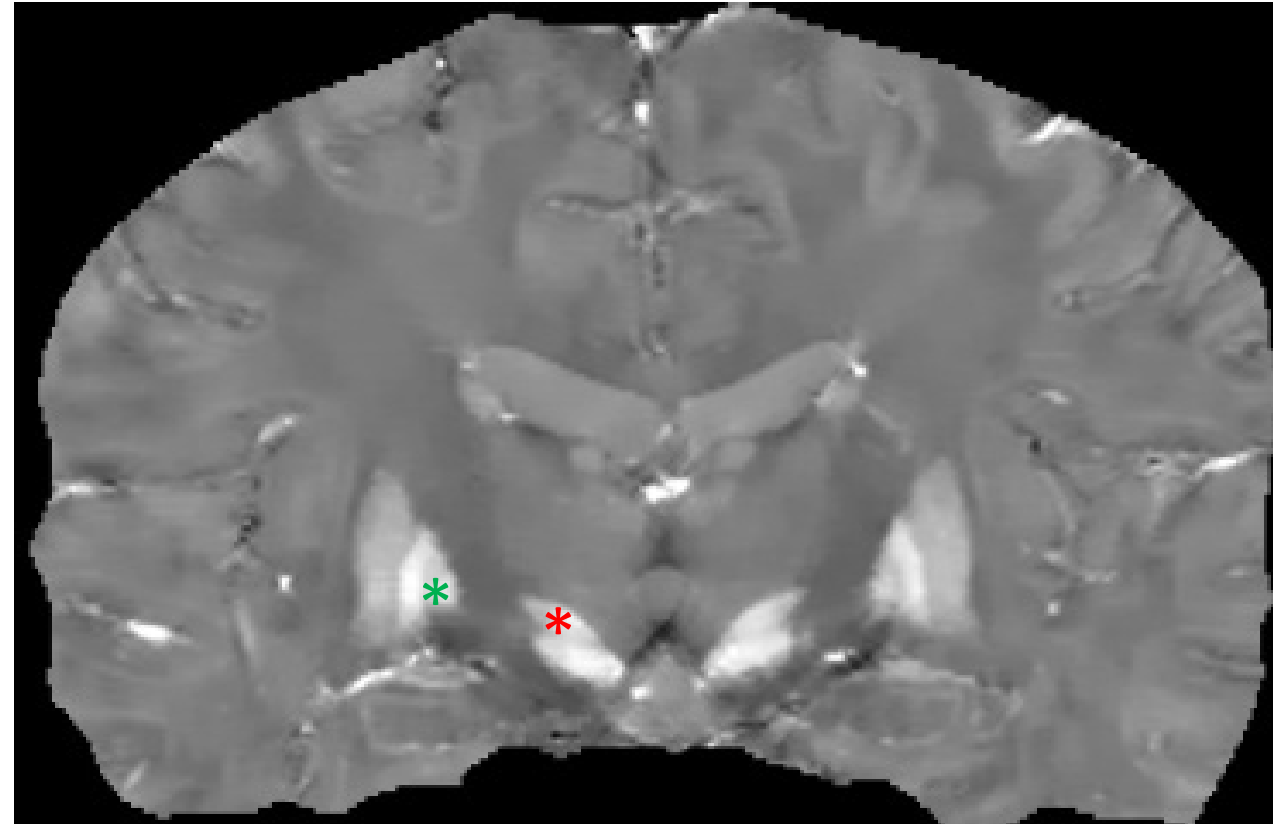
# Rechargeable batteries





# Targets

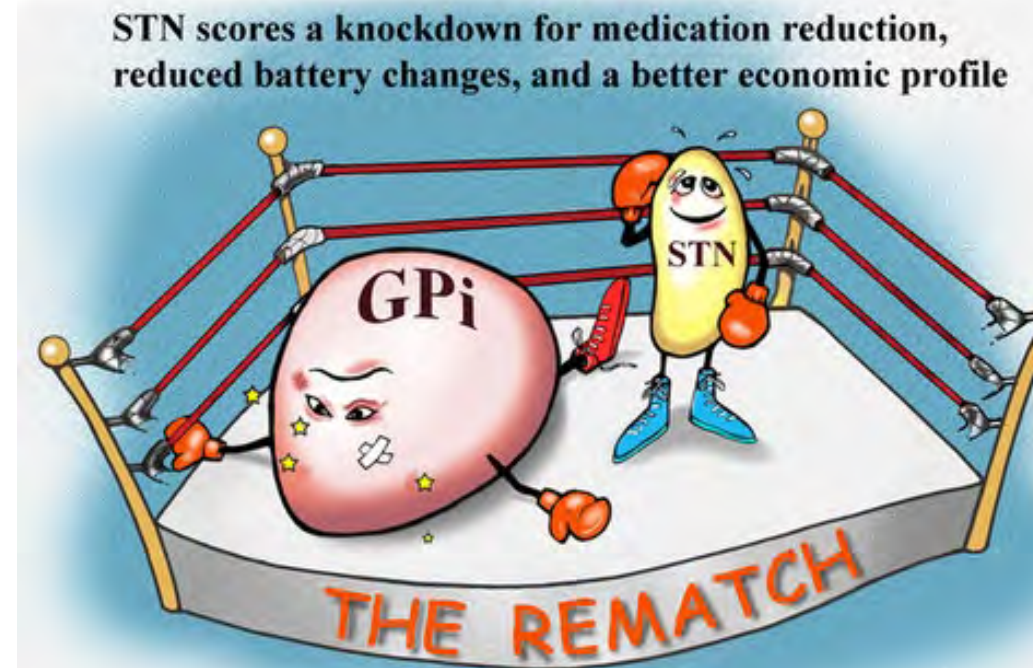
- Subthalamic nucleus
- Globus pallidus interna





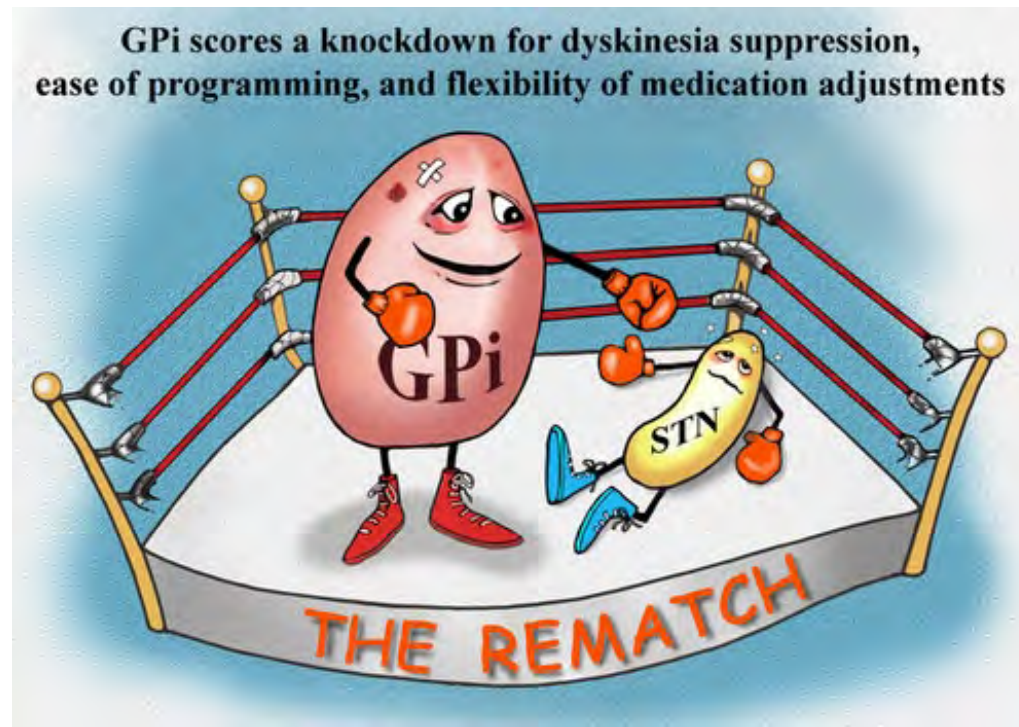
# Targets: STN

- Medication reduction...
- Faster tremor control...



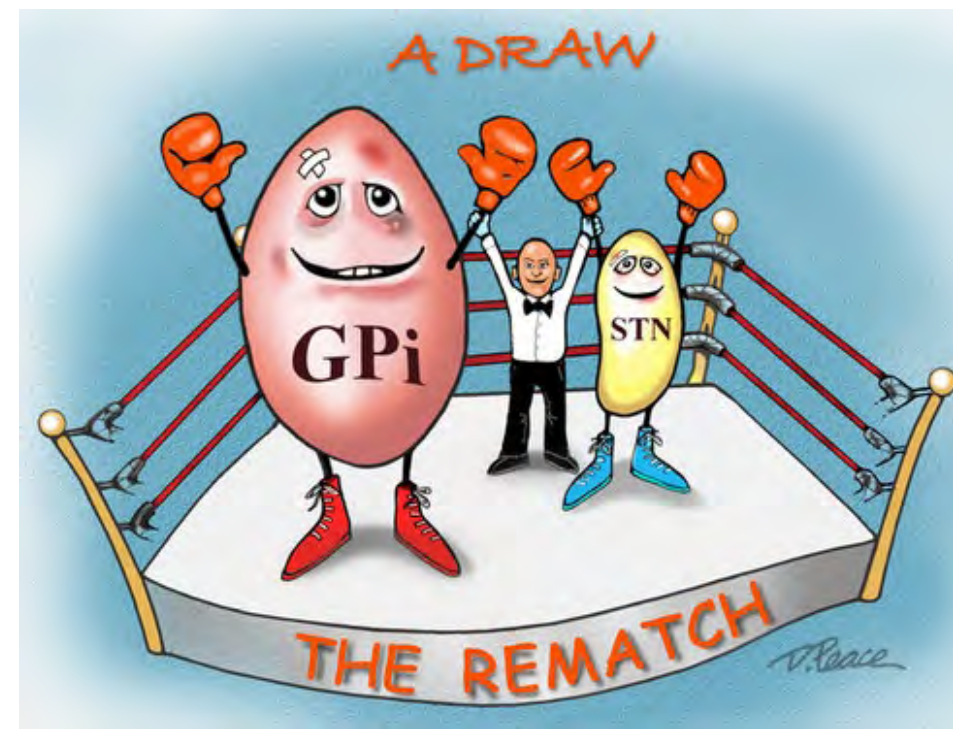
# Targets: GPi

- Dyskinesias...
- Dystonia...
- Easy programming and flexible med adjustments



# Targets: GPi and STN

- Both targets equivalent in overall motor benefit
- Team expert with both targets
- Personalize based on patient needs!





# Imaging at UNMC

- MRI under general anesthesia
- At least 2 weeks before procedure







# Imaging at UNMC





# Imaging at UNMC





# Surgery



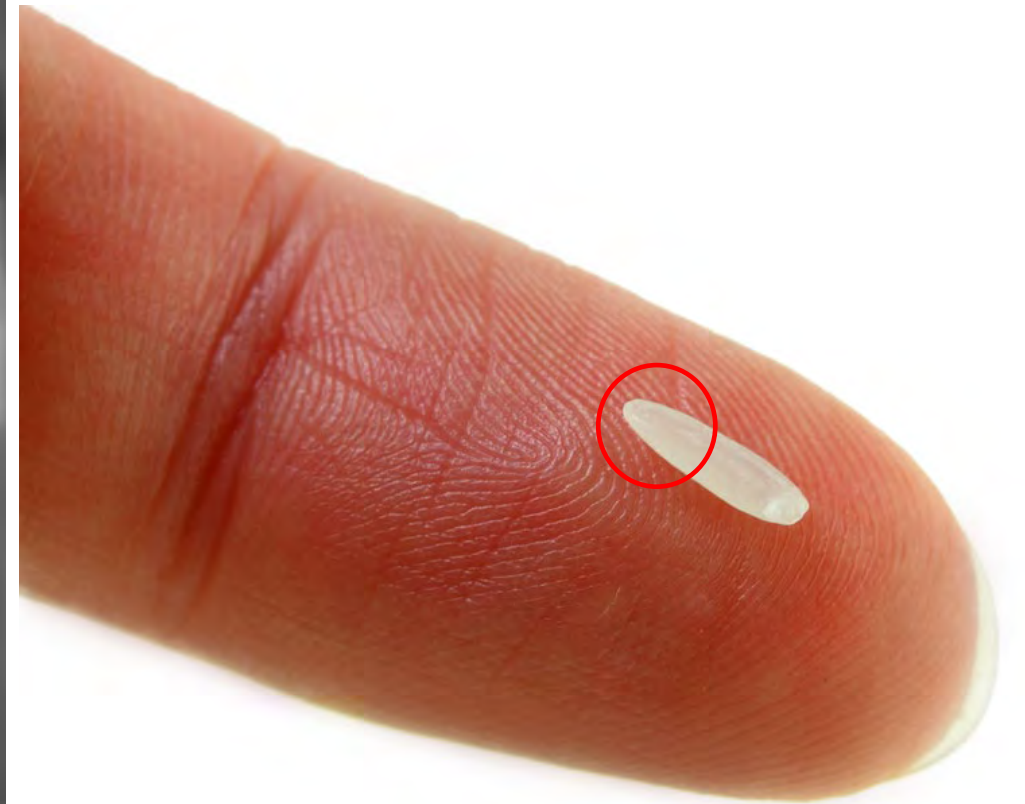


# Sleep vs Awake Surgery





# Planning: Targeting



# Millimeters matter!





# Millimeters matter!



## Mirthful Laughter Induced by Subthalamic Nucleus Stimulation

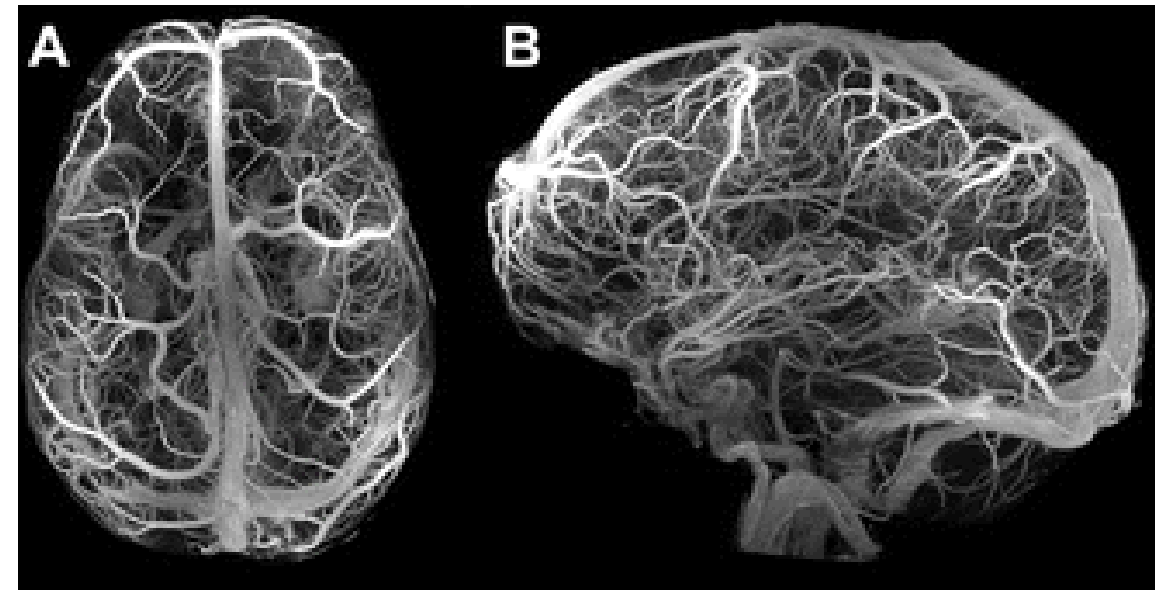
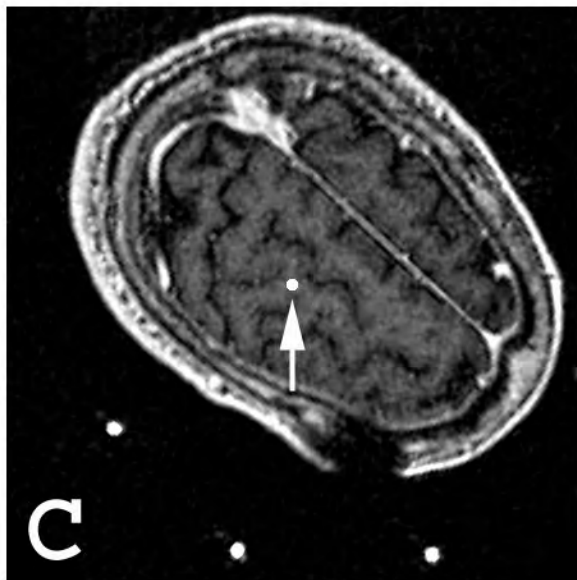
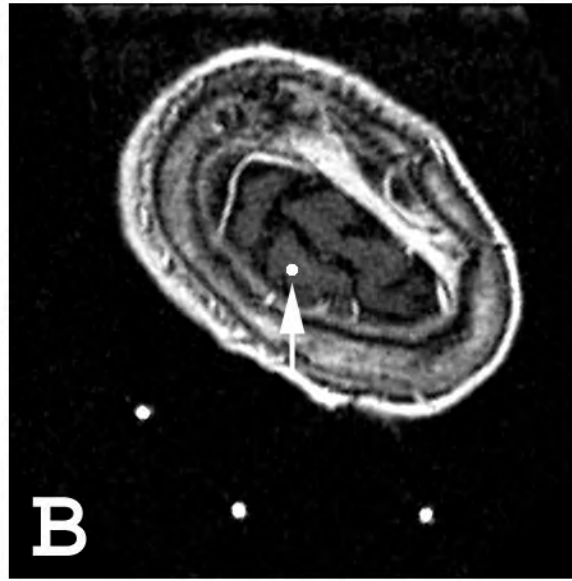
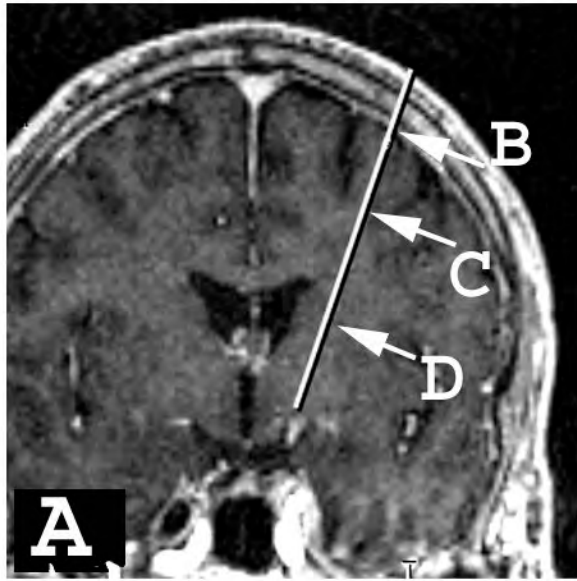
Paul Krack, Rajeev Kumar, Claire Ardouin,  
Patricia Limousin Dowsey, John M. McVicker,  
Alim-Louis Benabid, and Pierre Pollak

*Movement Disorders*  
Vol. 16, No. 5, pp. 867-875  
© 2001 The Movement Disorder Society

## Mirthful Laughter Induced by Subthalamic Nucleus Stimulation

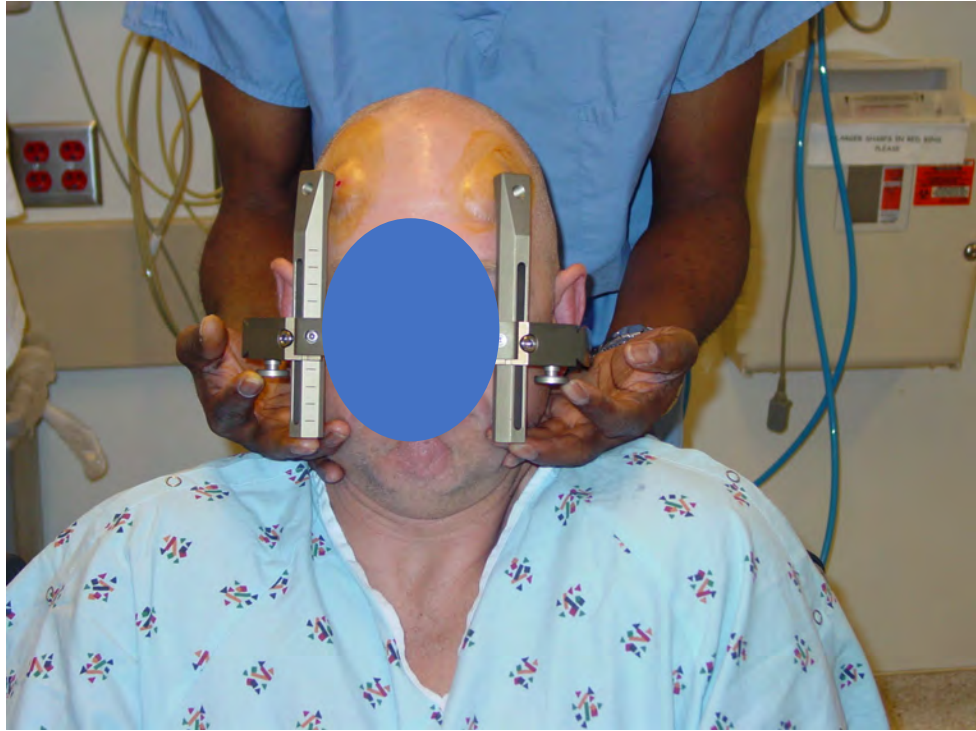
Paul Krack, MD,<sup>1,2\*</sup> Rajeev Kumar, MD,<sup>3</sup> Claire Ardouin, PhD,<sup>1</sup> Patricia Limousin Dowsey, MD, PhD,<sup>1,4</sup>  
John M. McVicker, MD,<sup>3</sup> Alim-Louis Benabid, MD, PhD,<sup>1</sup> and Pierre Pollak, MD<sup>1</sup>

# Planning: Vessels





# Procedure: Frame placement



# Procedure: Frame placement





# Procedure: Set up



# Procedure: Set up



What is a really nice feature



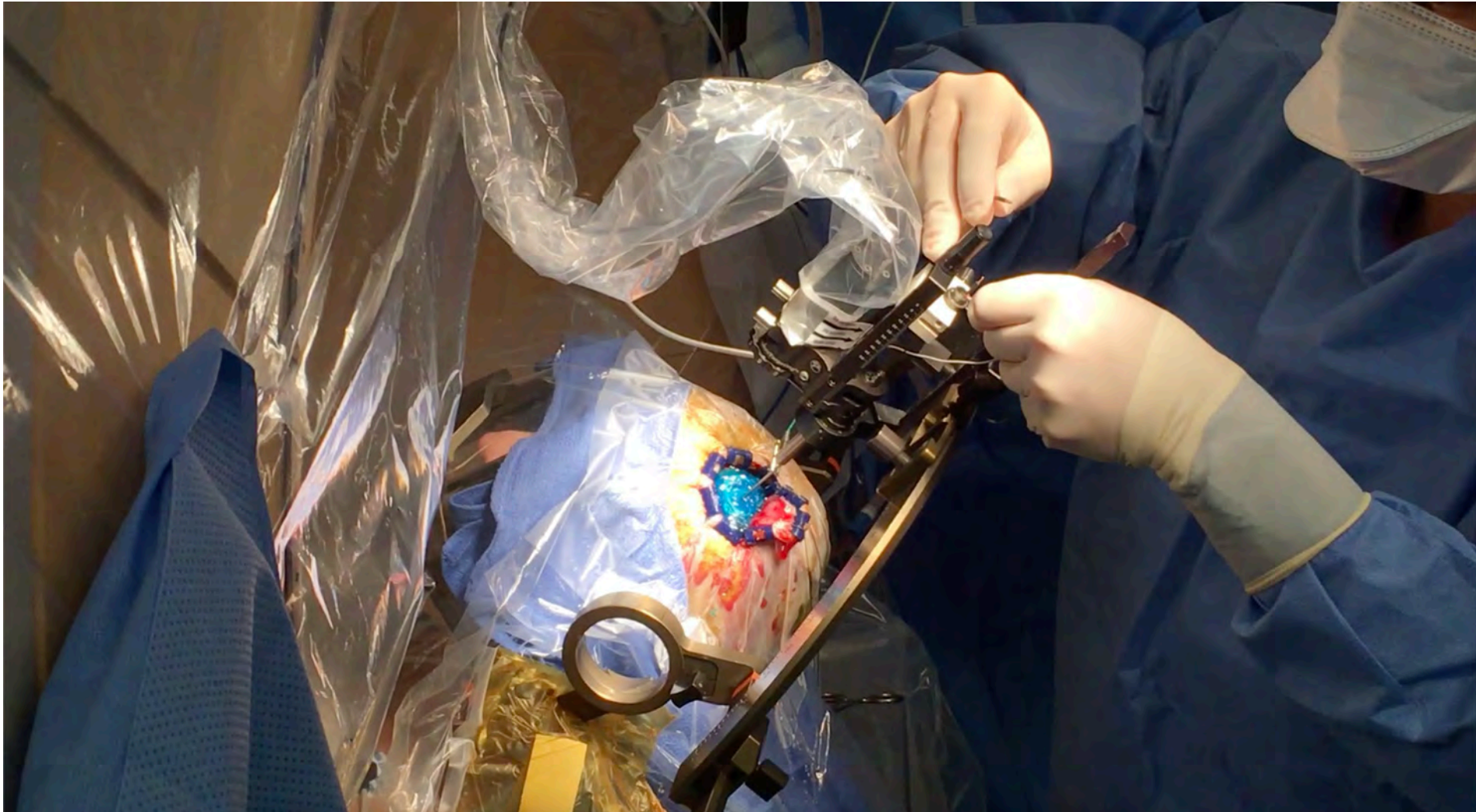


# Asleep-Awake-Asleep Surgery

- Patient will be **sedated** for skin incision and burr hole placement



# Procedure: Asleep





# Asleep-Awake-Asleep Surgery

- Patient will be **sedated** for skin incision and burr hole placement
- Patient will be **awakened** for brain mapping and electrode insertion





# Asleep-Awake-Asleep Surgery

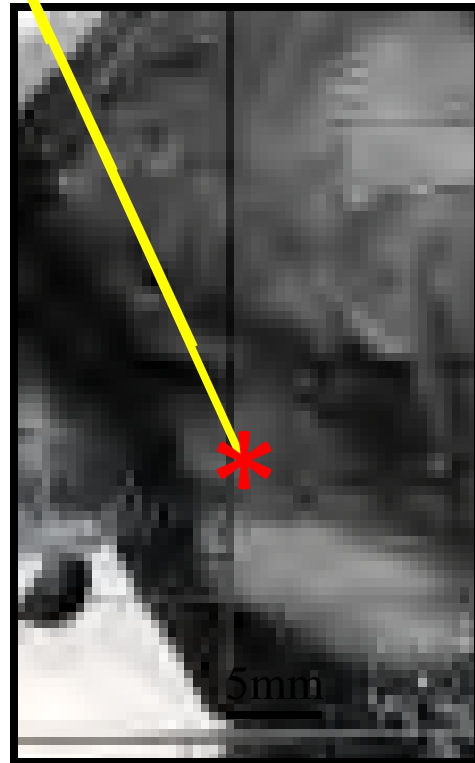
- Patient will be **sedated** for skin incision and burr hole placement
- Patient will be **awakened** for brain mapping and electrode insertion
  - Motor symptoms **does NOT manifest in the sleeping state**





# Procedure: Recordings

Position of electrode

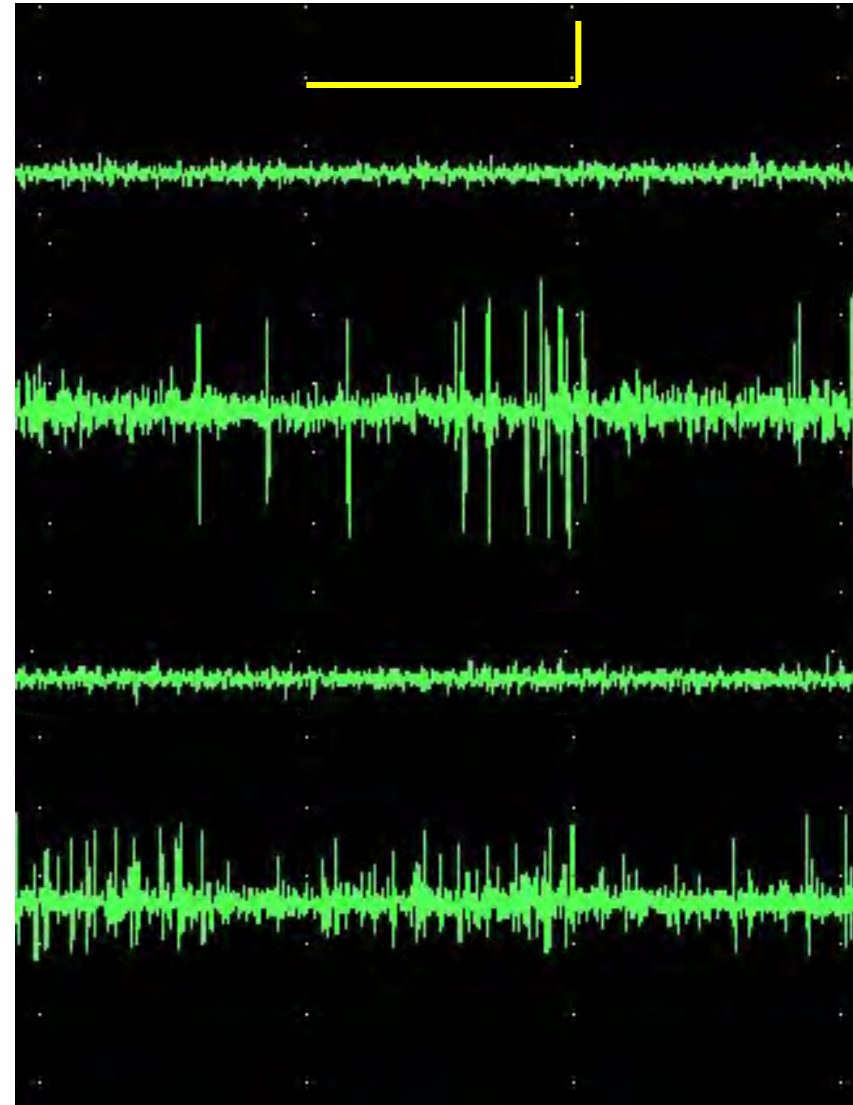


White matter

Thalamus

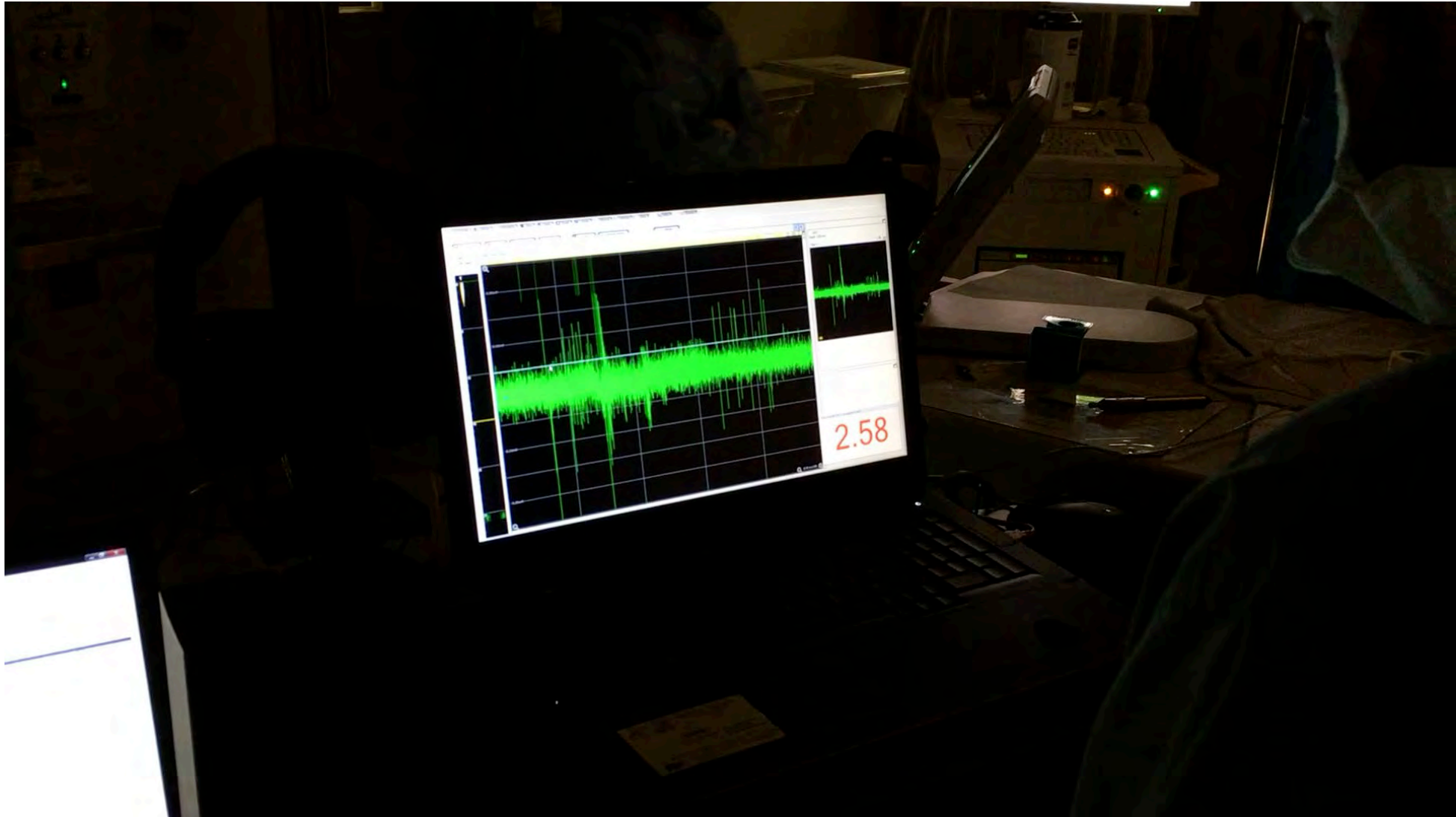
Zona incerta

STN

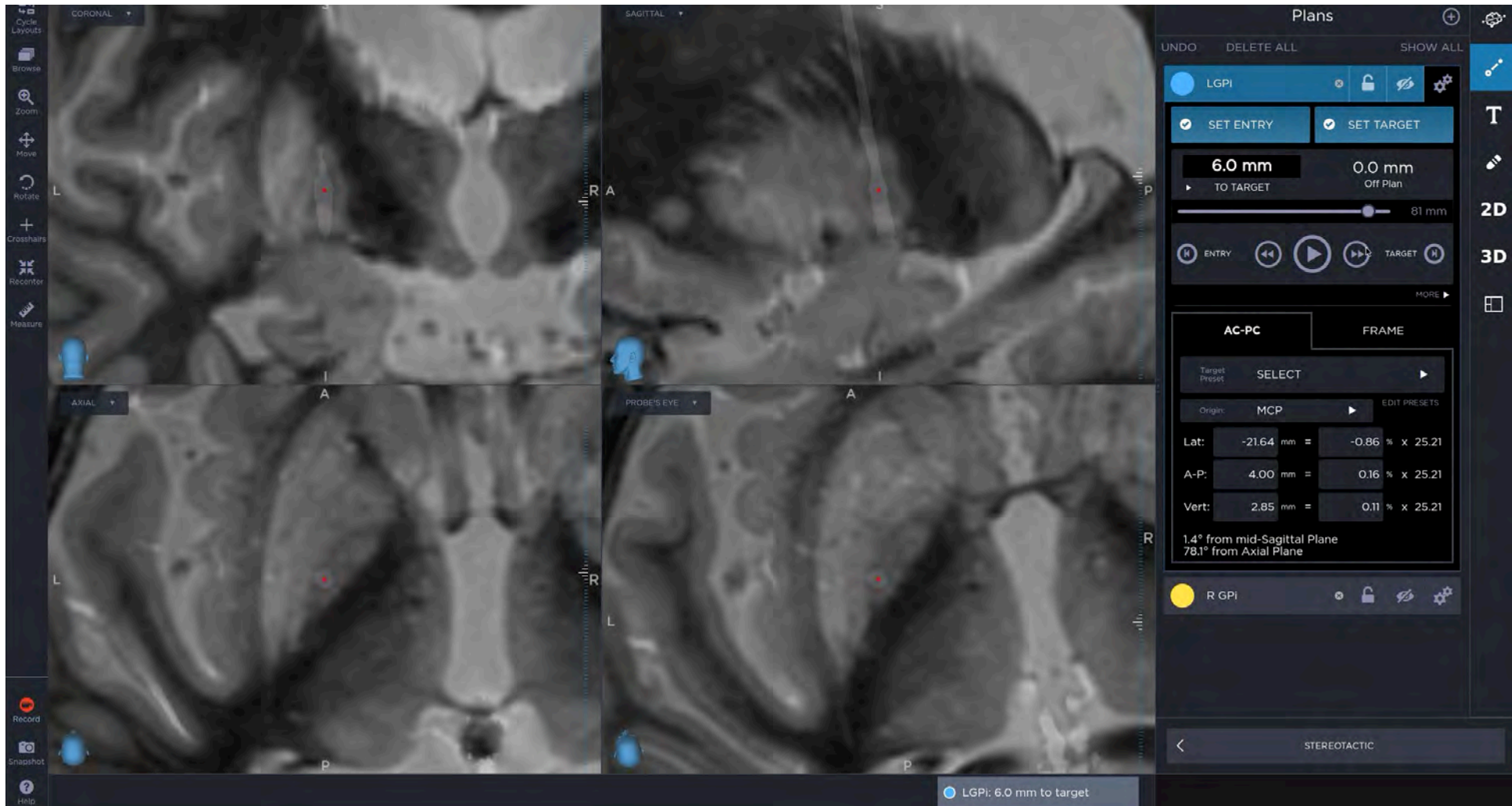




# Procedure: Recordings



# Procedure: Imaging Confirmation





# Procedure: Clinical testing

- Clinical benefit at low current: 0.5 mA
- Side effects at high voltages: > 4 mA
- Wider therapeutic window







# Procedure: Clinical testing





# Asleep-Awake-Asleep Surgery

- Patient will be **sedated** for skin incision and burr hole placement
- Patient will be **awakened** for brain mapping and electrode insertion
  - Motor symptoms **does NOT manifest in the sleeping state**
- Patient will go **back to sleep** for closure



# Procedure: generator placement





# Complications

- Hemorrhage: 3% Usually minor, no symptoms
- Severe Hemorrhage: 1%







# Complications

- Hemorrhage: 3% Usually minor, no symptoms
- Severe Hemorrhage: 1%
- Infection: 3 %. Leads vs IPG.. Management?





# Complications

- Hemorrhage: 3% Usually minor, no symptoms
- Severe Hemorrhage: 1%
- Infection: 3 %. Leads vs IPG.. Management?
- Hardware related: 3%, including misplaced leads.. What to do?





**After surgery**





# What is important after surgery?

- Parkinson's medication
  - DBS is not ON
- Early ambulation
  - Speeds up recovery
  - Discharge next day after surgery







# What is important after surgery?

- Communication Communication Communication
- Check your incisions!





# What is happens after surgery?

- Precise Programming
  - Movement Disorder Neurologist
  - Advanced practice provider
  - Nurses
- Time and patience!
- Medication and stimulation adjustments



## Study Cites Preventable Reasons for DBS Failure

*Many of the errors were either avoidable or correctable by more experienced physicians.*

derwent the following types of DBS im-  
plantation: 21, bilateral subthalamic nu-  
cleus; 8, unilateral subthalamic nucleus; 8,  
unilateral ventral intermediate nucleus;

▶ Incorrect diagnosis (10 instances).  
▶ Inadequate medication trial/dementia  
(10).  
▶ Misplaced leads (19).

# Conclusions

- Experience counts: More experience > better outcomes
- Proper patient selection



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- Minimize complications: Safe surgical technique
- Maximize benefit: Accurate electrode placement



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# Conclusions

- Experience counts: More experience > better outcomes
- Proper patient selection
- Minimize complications: Safe surgical technique
- Maximize benefit: Accurate electrode placement
- Personalization of therapy based on your goals!





# Balance and Gait Research in Parkinson's Disease

**Carolyn Curtze, PhD**

Assistant Professor, Department of Biomechanics

University of Nebraska at Omaha

**Grant Support**

NIH NIGMS, P20GM109090

Nebraska Research Initiative

Medtronic

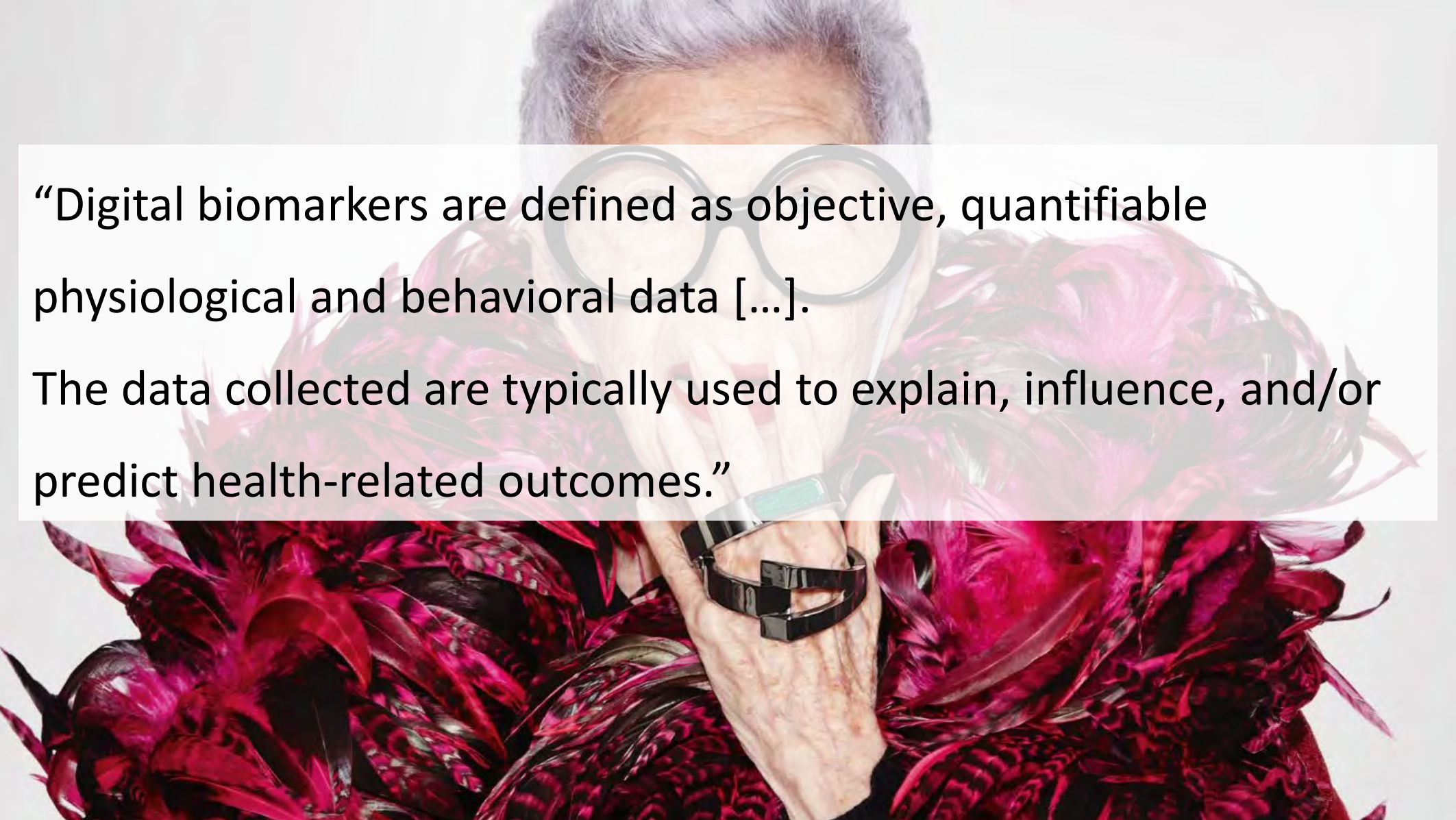
Medical Research Foundation of Oregon

**Carolyn Curtze, PhD**

[ccurtze@unomaha.edu](mailto:ccurtze@unomaha.edu)





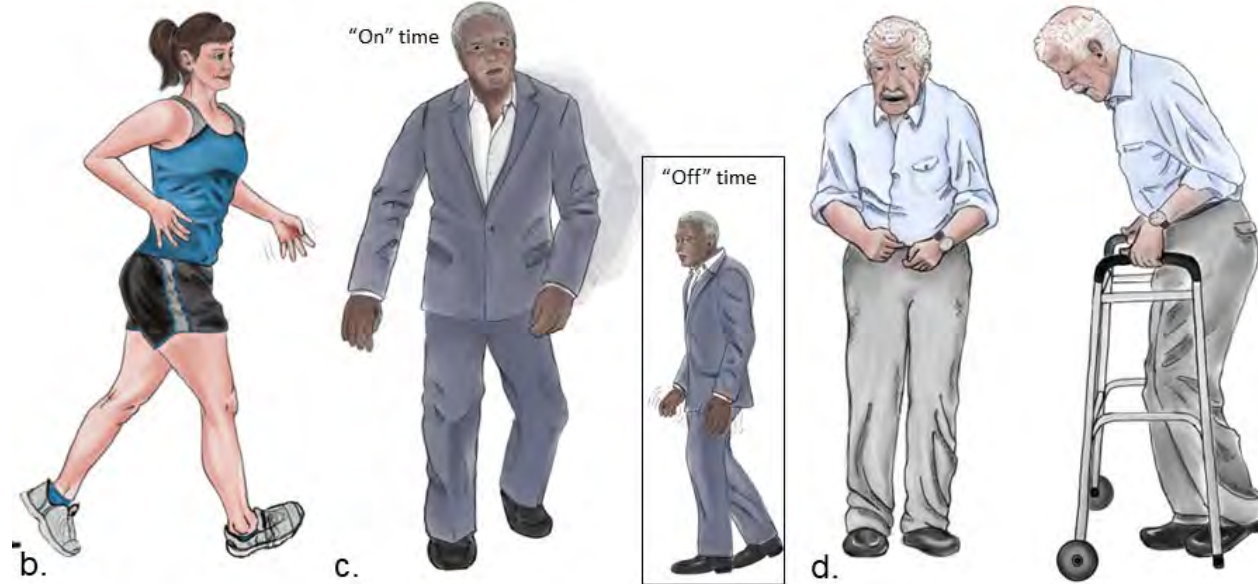


“Digital biomarkers are defined as objective, quantifiable physiological and behavioral data [...].

The data collected are typically used to explain, influence, and/or predict health-related outcomes.”



- Tremor
- Bradykinesia
- Rigidity
- Postural Instability



Armstrong & Okun (2020)

Levodopa is the standard treatment of Parkinson's disease.



- Small & Lightweight
- Rechargeable or replaceable batteries
- Battery life of hours to days
- One to many sensors on body segments
- Store & download or real time streaming
- Wireless synchronization





# Measures of Mobility

## Posture



30 seconds

- P - Sway RMS AP ( $m/s^2$ )
- P - Sway RMS ML ( $m/s^2$ )
- P - Mean velocity AP (m/s)
- P - Mean velocity ML (m/s)
- P - Centroidal Frequency AP (Hz)
- P - Centroidal Frequency ML (Hz)
- P - Frequency Dispersion AP (-)
- P - Frequency Dispersion ML (-)
- P - Normalized Jerk AP (-)
- P - Normalized Jerk ML (-)

## Initiation



- I - APA Duration (s)
- I - APA Latency (s)
- I - APA Peak AP (g)
- I - APA Peak ML (g)
- I - RoM First Step (deg)
- I - Duration of First Step (s)

## Gait



7 meters

- Gait - Pace**
- G - Gait Cycle Time(s)
  - G - Cadence (steps/min)
  - G - Stride Velocity (%h/s)
  - G - Stride Length (%h)
  - G - RoM Leg (deg)

- Gait - Arm & Trunk**
- G - Arm Peak Velocity (deg/s)
  - G - Arm Swing RoM (deg)
  - G - Asymmetry Arm Swing RoM (%)
  - G - RoM Trunk Frontal Plane (deg)
  - G - RoM Trunk Sagittal Plane (deg)
  - G - RoM Trunk Horizontal Plane (deg)

- Gait - Dynamic Stability**
- G - Double Support Time (%)
  - G - Stance Time (%)
  - G - Swing Time (%)

## Turning

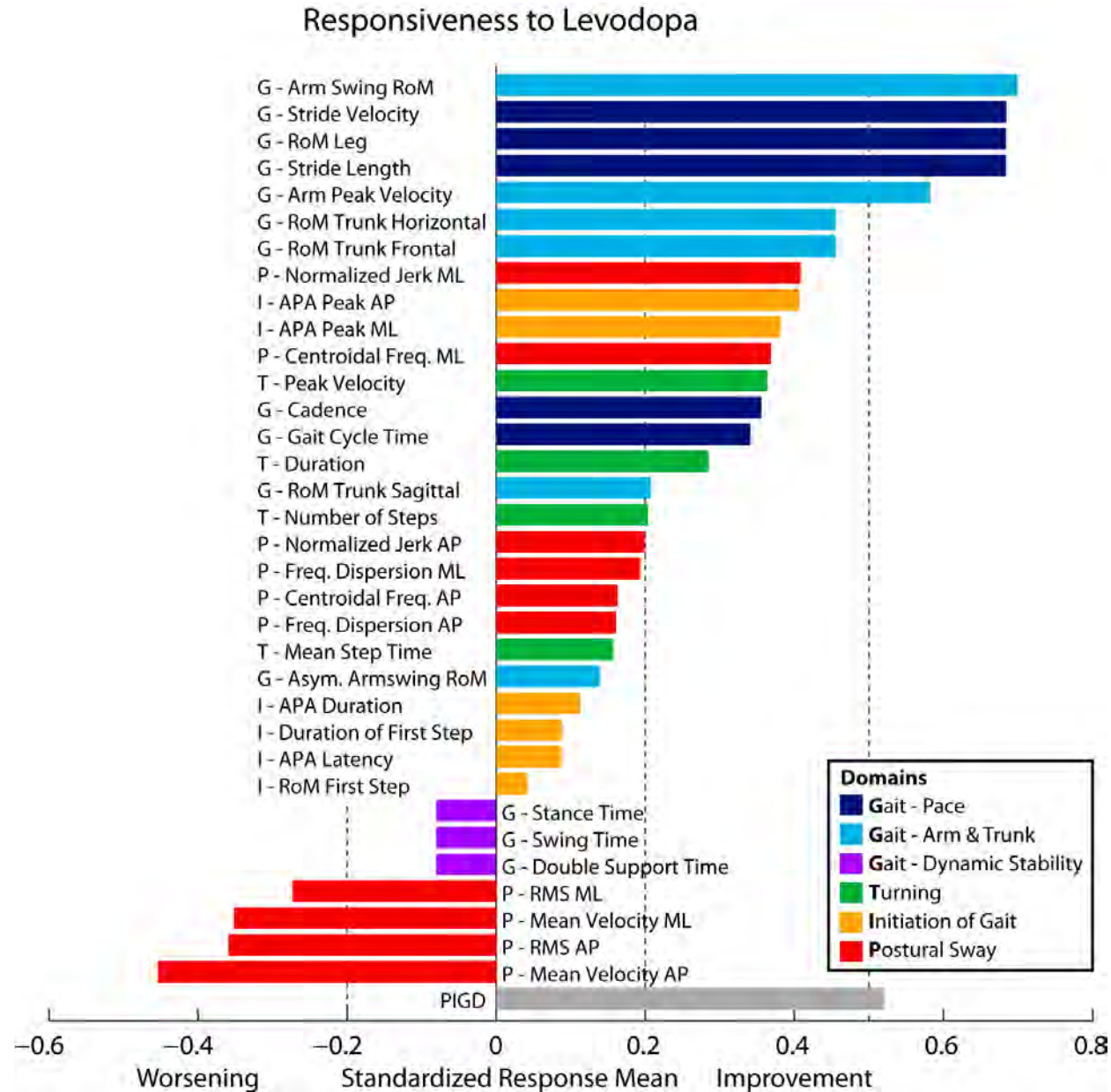


180°

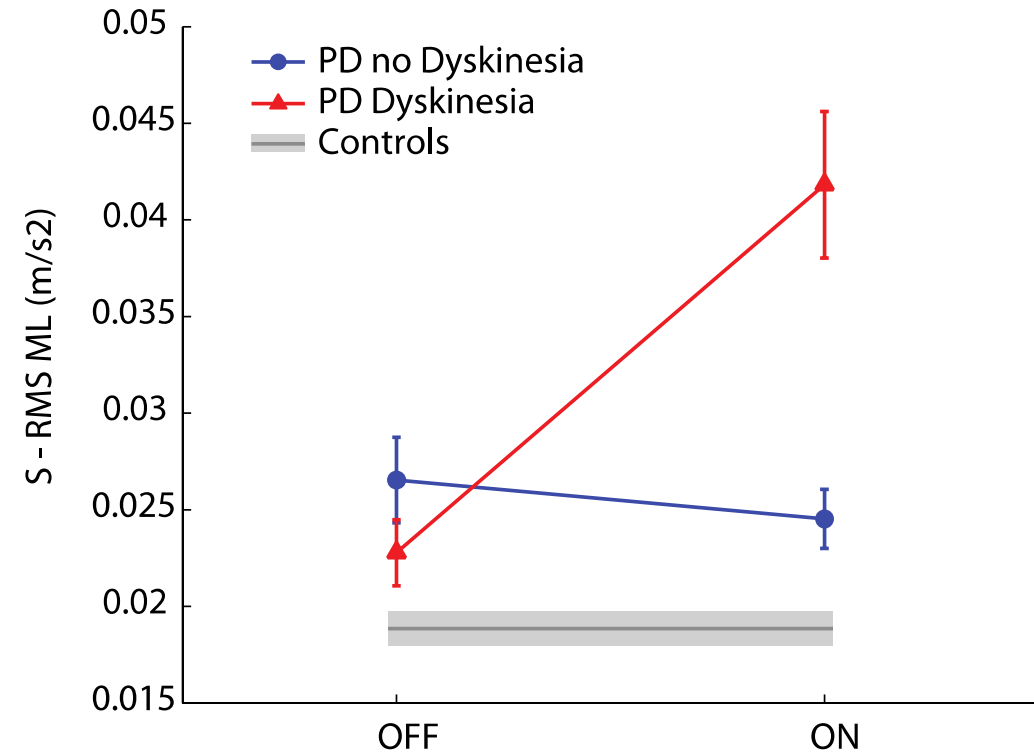
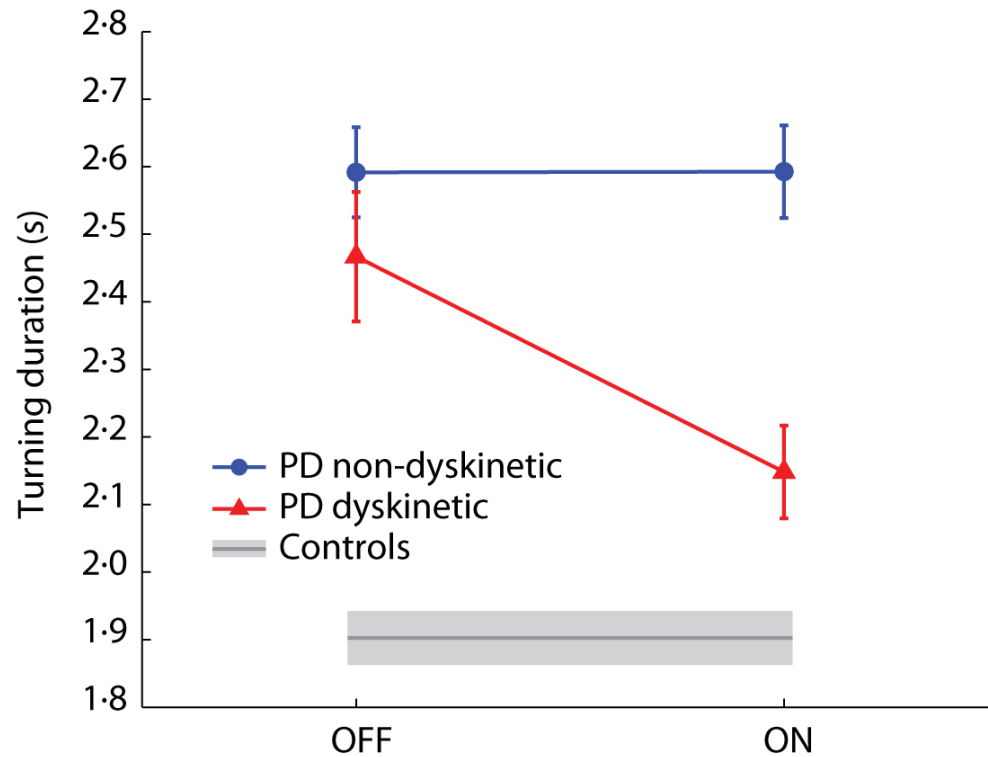
- T - Peak Velocity (deg/s)**
- T - Duration (s)
  - T - Mean Step Time (s)
  - T - Number of Steps (n)



# Levodopa is a Double-edge Sword



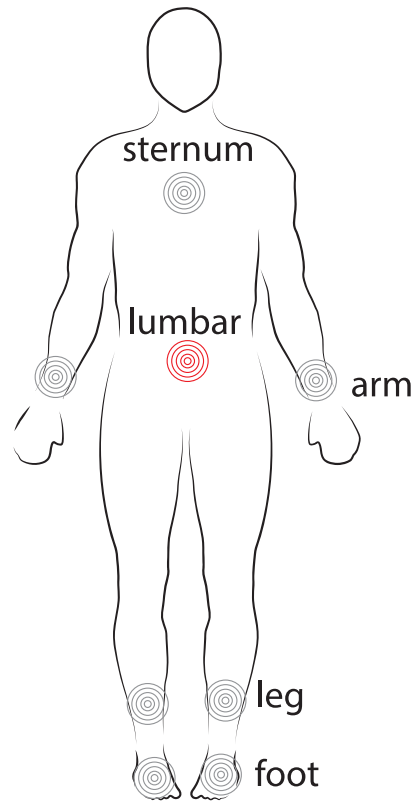
# Levododopa is a Double-edge Sword





What is balance?

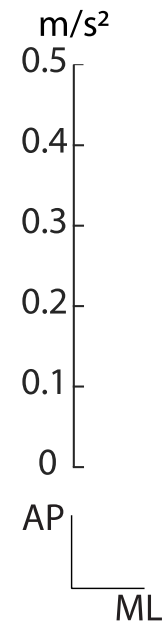
## Sensor Placement



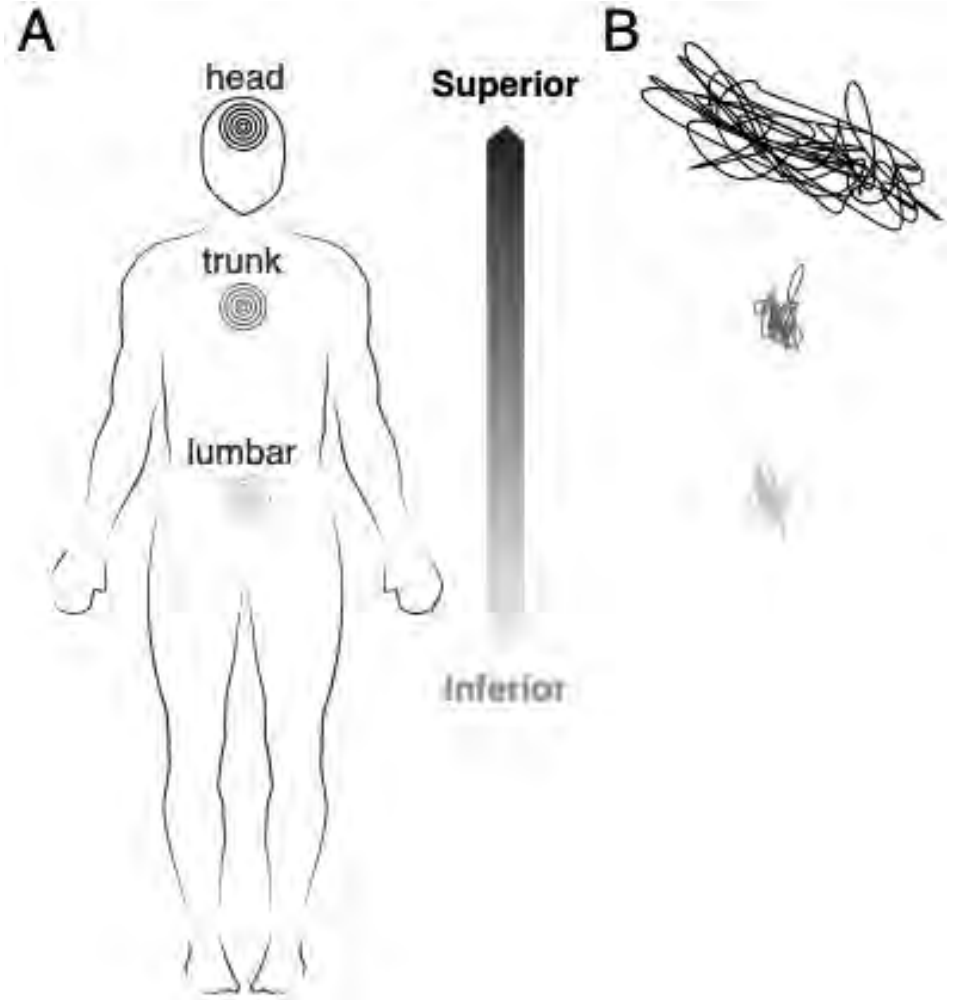
## Postural Sway

OFF state

ON state with dyskinesia







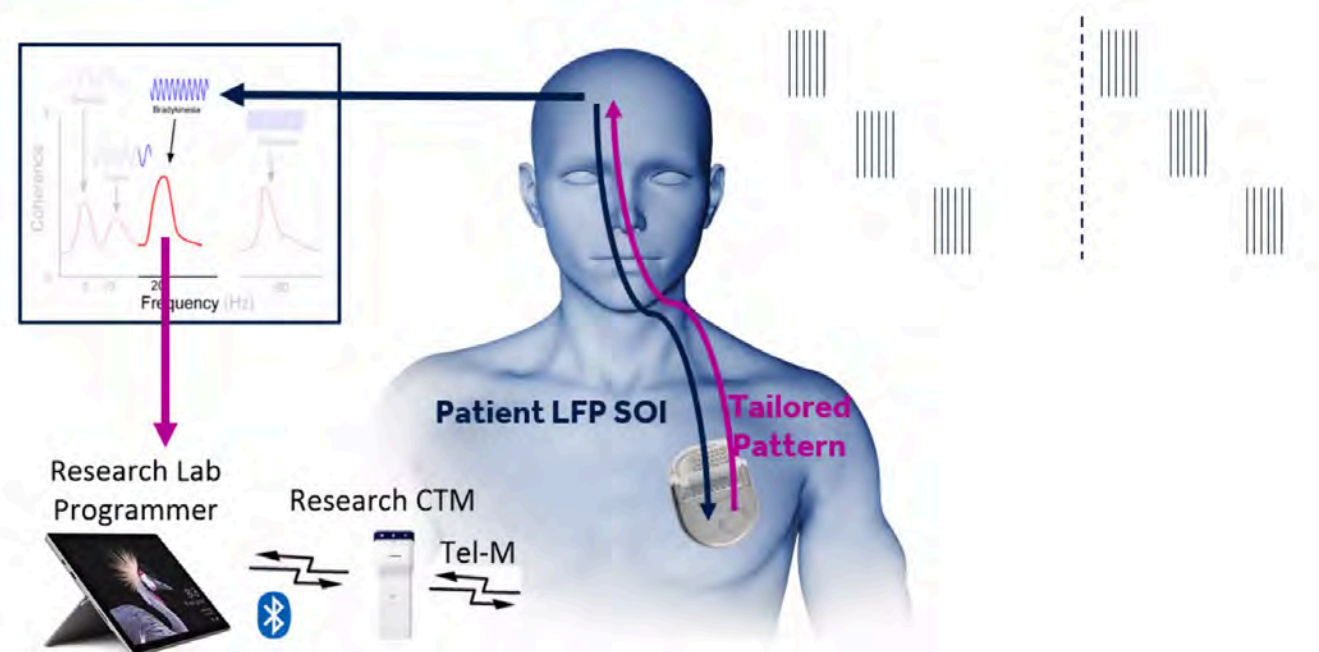


# Deep Brain Stimulation

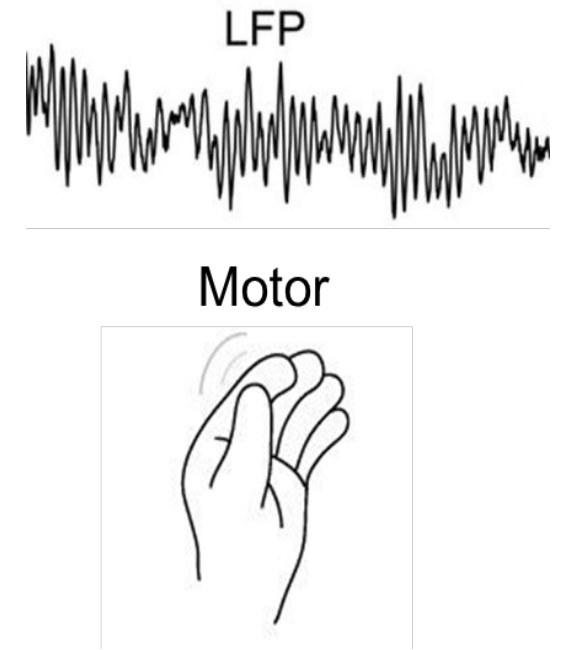
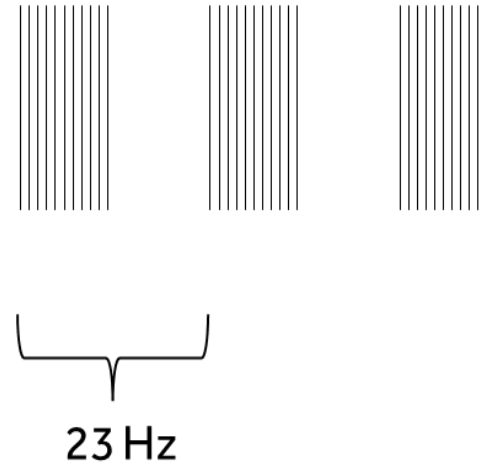
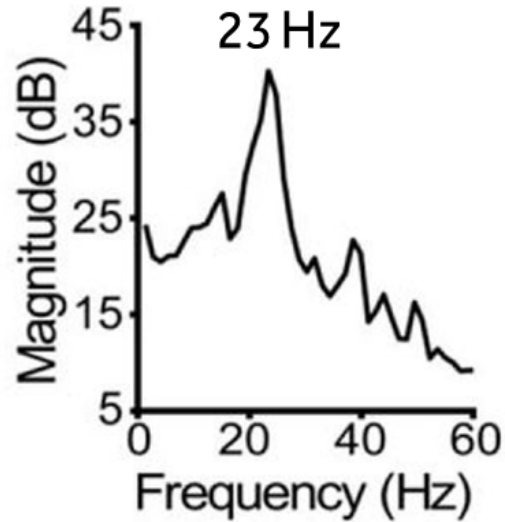
Neuromodulation

## DBS Electrode Switching Patterns in Parkinson's disease

- Study Population
  - 10-15 study subjects total, optimized for clinical stimulation and medication, 3 months post-surgery
- Study Design
  - Open-label, non-randomized, proof-of-concept assessment of clinical and research stimulation







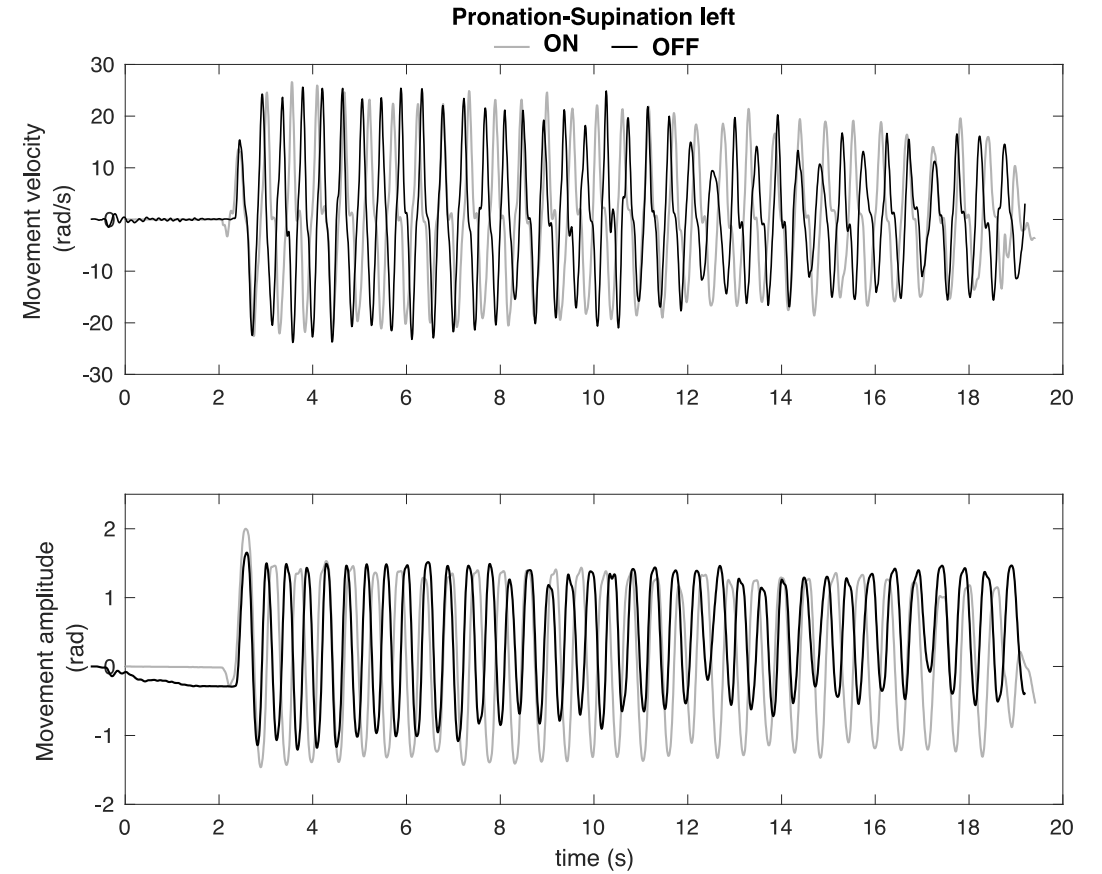
**Sense**  
Patient specific oscillations



**Tune Stim Pattern**  
Based on sensing



**Implement & Evaluate**  
Sensing and Clinical Scores





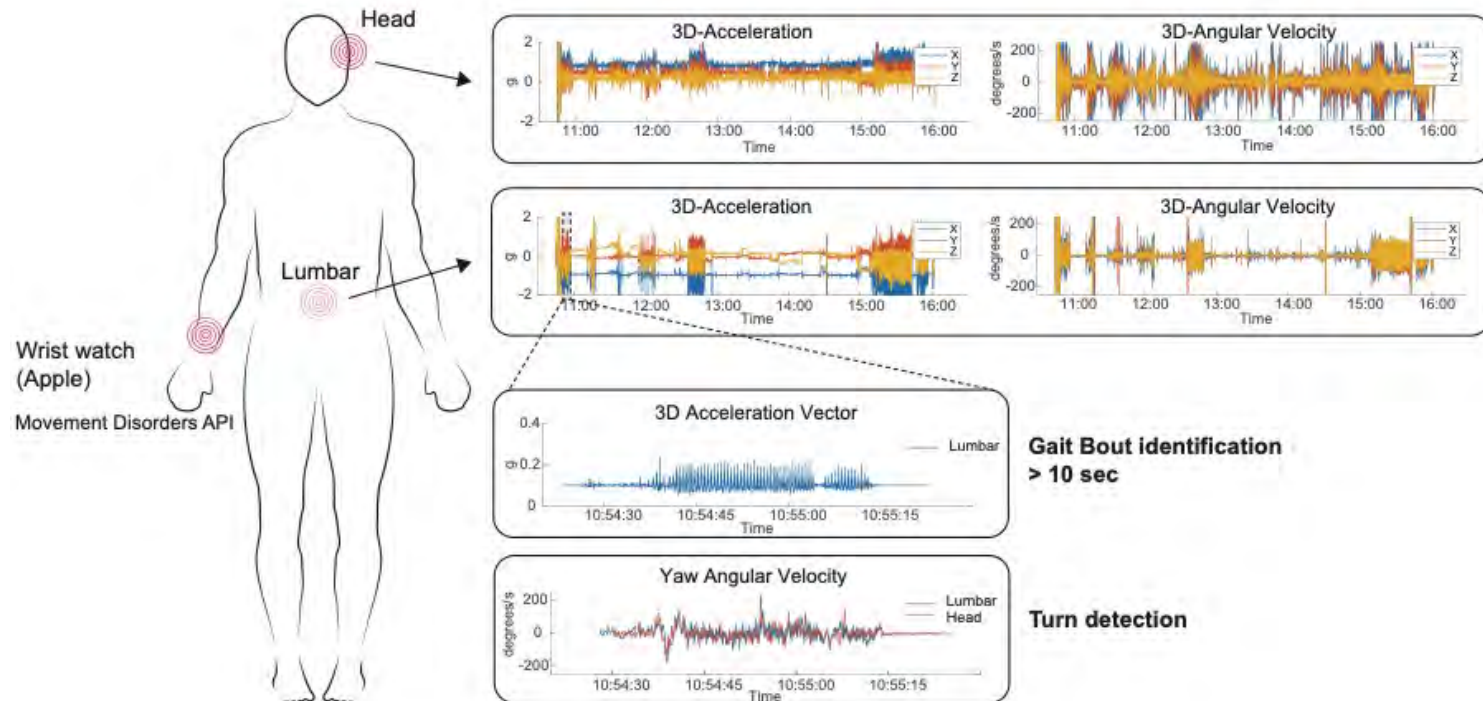


To manage her Parkinson's disease, Sara Riggare spends 1 hour in neurological healthcare and 8,765 hours in selfcare per year.

## Why continuous monitoring?

# Why continuous monitoring?

The assessment of mobility in the clinic may not adequately reflect variability during daily life.



Can technology be used for detection of turning and walking at home?







# Thank you!

**Carolyn Curtze, PhD**

Assistant Professor

Department of Biomechanics University  
of Nebraska at Omaha

[ccurtze@unomaha.edu](mailto:ccurtze@unomaha.edu)



# Balancing Nutrition & GI Issues in Parkinson's Disease

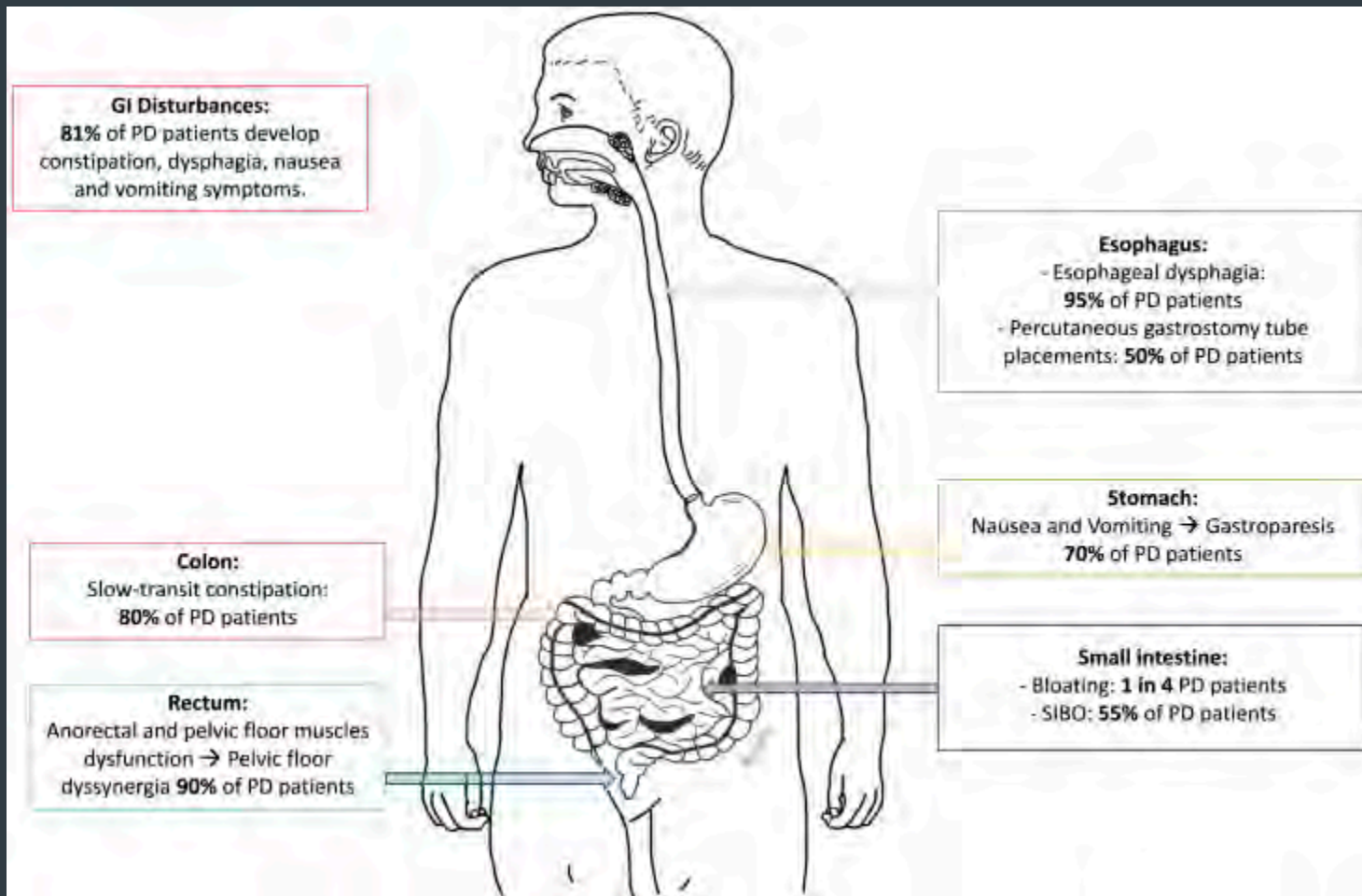
Jenna Wuebker, MS, RD, LMNT, LD  
Nutrition Therapist  
Nebraska Medicine Neurological Sciences

# Gastrointestinal Issues

- As many as 81% of patients with PD develop GI problems
- Affects quality of life
- Correlated with worse anxiety and depression







Pasricha TS, Guerrero-Lopez IL, Kuo B. Management of Gastrointestinal Symptoms in Parkinson's Disease: A Comprehensive Review of Clinical Presentation, Workup, and Treatment. *J Clin Gastroenterol.* 2024;58(3):211-220. Published 2024 Mar 1. doi:10.1097/MCG.0000000000001961





# Nutritional Concerns with Gastrointestinal Issues

- Eating less
- Drinking less
- Unintentional weight loss
- Malnutrition
- Weakness
- Fatigue



# Nutrition Goals

- Maximize nutritional intake safely to avoid nutritional issues
  - Simultaneously while working with your doctor on the cause and treatment
- Avoid weight loss



# Gastrointestinal Issues

1. Nausea
2. Gastroparesis
3. Constipation
4. Dysphagia



# Nausea



# Nausea

- Queasy or uneasy feeling in stomach
- May lead to vomiting in severe cases
- Can be a side effect from medications such as carbidopa-levodopa
- Can occur as a secondary effect of gastroparesis or constipation



# Nutrition Strategies - Nausea

- Have food with medications if safe to do so
  - Carbidopa-levodopa: Okay to take with carbohydrates such as fruit, crackers, pretzels, toast, dry cereal
- Eat light, bland foods
  - Crackers
  - Toast
  - Pretzels
  - Rice
  - Potatoes
  - Pasta



# Nutrition Strategies - Nausea

- Try cold foods
  - Gelatin
  - Pudding
  - Applesauce
  - Ice cream
  - Chilled fruit
  - Yogurt
  - Custard
  - Popsicles
- Avoid strong flavors, greasy foods and fried foods
  - Spicy foods
  - Fast food
  - Deep fat fried foods



# Nutrition Strategies - Nausea

- Eat and drink slowly.  
Have something to eat every 1-2 hours.
- Try ginger or peppermint tea

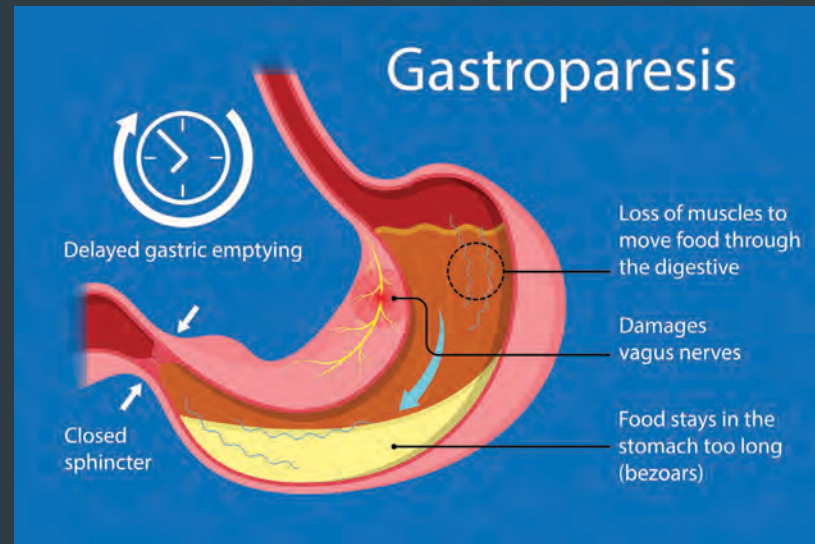




# Gastroparesis

# Gastroparesis

- Delayed stomach emptying
- Food sits in stomach longer than normal
- Can be diagnosed with gastric emptying study
  - Many patients with PD do not have symptoms



# Gastroparesis

- Only FDA-approved medication for gastroparesis, metoclopramide (Reglan) should be avoided
  - Blocks dopamine receptors in brain
  - PD symptoms may worsen
- Other treatments can be considered



# Nutrition Strategies - Gastroparesis

- Have smaller, more frequent meals and snacks
  - Breakfast
  - Morning snack
  - Lunch
  - Afternoon snack
  - Dinner
  - Evening snack
- Avoid foods that increase acid reflux
  - Acidic foods
  - Spicy foods
  - Fried foods
  - Greasy foods
  - Caffeine
  - Mint





# Nutrition Strategies - Gastroparesis

- Choose low fat solid foods
  - Chicken
  - Turkey
  - Fish
  - Lean beef
  - Egg whites
  - Low fat ice cream
  - Low fat yogurt
  - Low fat cottage cheese
  - Choose oils over butter
  - Broth
  - Gelatin
  - Popsicles
- Choose low fiber foods
- Aim for 2 grams of fiber or less per serving
  - Saltine crackers
  - Graham crackers
  - Puffed rice cereal
  - Cream of rice
  - Cream of wheat
  - Grits
  - Pretzels
  - White bread
  - White rice
  - Canned vegetables without seeds, skins, hulls
  - Cooked carrots
  - Mashed potatoes
  - Sweet potato
  - Canned fruit without seeds, skins, membranes
  - Applesauce
  - Banana



# Nutrition Strategies - Gastroparesis

- High fat liquids may be tolerated
  - Milkshakes
  - Smoothies made with cream
- Avoid carbonated beverages which can lead to bloating
  - Soda
  - Carbonated water



# Nutrition Strategies - Gastroparesis

- Chew foods well before swallowing. Consider ground or pureed foods.
- Utilize oral nutrition supplements

Product	Calories
Boost Very High Calorie	530
Boost Plus	360
Ensure Plus	350
Ensure Complete	350
Naked Juice Protein	~400
Bolthouse Farms Protein Plus	~400
Orgain Organic Nutrition Shake	250
Carnation Breakfast Essentials	240



# Constipation



# Constipation

- Often appears before motor symptoms up to 20 years before diagnosis
- Slow transit constipation or pelvic floor dysfunction

## Causes

- Changes in nerve cells of intestines
- Slowing of intestinal muscles
- Medication side effects
- Decrease in physical activity
- Inadequate fluid intake
- Changes in dietary intake



# Definition of Constipation

- Fewer than 3 stools a week
- Hard, difficult to pass stools

## Symptoms:

- Hard, dry or lumpy stools
- Straining or pain when passing stools
- A feeling that not all stool has passed
- A feeling that the rectum is blocked
- The need to use a finger to pass stool



# Nutrition Strategies - Constipation

## Slow transit constipation

- Increase fiber
- Increase water
- Increase physical activity
- Probiotics

## Pelvic floor dysfunction

- Do pelvic floor physical therapy



# Nutrition Strategies - Constipation

## Fiber

- Fruits: passion fruit, guava, raspberries, blackberries, pear, avocado, kiwi, blueberries
- Vegetables: peas, artichoke, Brussels sprouts, kale, sweet potato, beets, broccoli, carrots
- Whole Grains: bulgur, quinoa, whole wheat pasta, oatmeal, brown rice, whole wheat bread, bran
- Nuts, Seeds & Legumes: chia seeds, lentils, black beans, pumpkin seeds, almonds, pistachios, pecans, ground flax seed
- Prunes and prune juice





# Nutrition Strategies - Constipation

## Tips for Adding Fiber

- Increase fiber SLOWLY
- Add 1 new fiber rich food at a time
- If difficulties increasing fiber through food, can try fiber supplement (Ex: Metamucil, Benefiber, Citrucel)



# Nutrition Strategies - Constipation

## Fluids

- Include water, 100% fruit juice, vegetable juice, milk, sports drinks, lemonade
- Foods with a higher water content: soup, broth, gelatin, pudding, yogurt, applesauce, watermelon, popsicles, smoothies
- Smooth Move tea
  
- How much do you need?
  - 25-35 mL/kg
  - Take weight in lbs and divide by 2 = ounces to drink
    - Ex: 150 lbs (56-80 oz)
    - Ex: 200 lbs (75-106 oz)



# Nutrition Strategies - Constipation

## Tips for Drinking More Fluids

- Be intentional
- Determine fluid goal
- Fill jug of water with goal amount
- Use water bottle
- Drink a glass of water each time you take medications
- Drink a glass of water with each meal
- Try flavored liquids

You will go to the bathroom  
more! 😊



# Nutrition Strategies - Constipation

## Physical Activity

- Decreases time it takes food to move through intestines
- Stimulates natural squeezing of muscles in intestines
- Walking, running, swimming, dancing, yoga, PD exercise classes





# Nutrition Strategies - Constipation

## Probiotics

- Live bacteria that can enhance gut microbiome
- Meta-analysis showed improved stool frequency and decreased number of laxatives needed



# Nutrition Strategies - Constipation

## Probiotics

### – Examples:

- The ***Lactobacillus*** genus, including *L. acidophilus*, *L. rhamnosus*, *L. casei* and *L. plantarum*
- The ***Bifidobacterium*** genus, including *Bifidobacterium longum* and *Bifidobacterium breve*

### – Sources:

- Yogurt
- Kefir
- Sauerkraut
- Kombucha



# Nutrition Strategies - Constipation

## **Chia seed pudding**

**Servings:** 4

**Ingredients:** 1/3 cup chia seeds  
1 1/2 cups milk  
2 Tablespoons maple syrup or honey  
1/2 teaspoon vanilla

**Optional ingredients/toppings:** Fruit, chopped nuts, coconut flakes

**Instructions:** Combine all ingredients in container with lid. Put lid on and shake ingredients. Chill for about an hour, then return to the container and shake it up. Let chill for at least 4 hours and overnight is even better. Chia seeds will expand and turn into the consistency of pudding/applesauce. Add optional ingredients/toppings before serving.



# Nutrition Strategies - Constipation

## Oats, Prune Juice, and Applesauce Constipation Remedy

**Ingredients:** 2/3 cup old fashioned oats

1/2 cup prune juice

1/2 cup applesauce

**Instructions:** Mix together all ingredients and store in the refrigerator. Have 2-4 Tablespoons a day or more as needed.



# Nutrition Strategies - Constipation

- If more help is needed...
  - Contact your doctor for recommendations on medications for constipation.
  - Stool softeners, laxatives, suppositories, enemas, etc.





# Dysphagia

# Dysphagia

- Involves any difficulty chewing or swallowing
- Can include issues with mouth, throat and esophageal muscles
  
- Important to see a Speech-Language Pathologist for a swallow assessment



# Nutrition Strategies - Dysphagia

- Follow diet texture and liquid consistency recommendations
  - Regular
  - Soft & bite sized
  - Minced & moist
  - Pureed
  - Thickener added to liquids
- Naturally pureed items
  - Applesauce
  - Pudding
  - Smooth yogurt
  - Ricotta cheese
  - Tomato soup
  - Refried beans
  - Mashed potatoes
  - Mashed sweet potatoes
  - Oatmeal
  - Cream of wheat
  - Cream of rice



# Nutrition Strategies - Dysphagia

- Have smaller, more frequent meals and snacks
  - Breakfast
  - Morning snack
  - Lunch
  - Afternoon snack
  - Dinner
  - Evening snack
- Drink liquids with calories and/or protein
  - Whole chocolate/strawberry milk
  - Hot cocoa made with whole milk
  - Milkshake
  - Malt
  - Kefir
  - Yogurt drinks
  - Fruit smoothie
  - Naked Juice
  - Fruit juice
  - Lemonade
  - Sports drinks



# Nutrition Strategies - Dysphagia

- Drink oral nutrition supplements

Product	Calories
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Ensure Plus	350
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Orgain Organic Nutrition Shake	250
Carnation Breakfast Essentials	240





# Nutrition Strategies - Dysphagia

- Mix in high calorie items
  - Oils
  - Butter
  - Mayonnaise
  - Ranch dressing
  - Gravy
  - Peanut butter
  - Cheese
  - Cream cheese
  - Sour cream
  - Heavy whipping cream
  - Coconut cream
  - Avocados
  - Pesto
  - Alfredo sauce



# Nutrition Strategies - Dysphagia

- May benefit from using a feeding tube if there are more significant swallowing issues
  - Used for nutrition, hydration and/or medications
  - Goes into the stomach
  - If safe to still eat or drink, can choose to have things you enjoy.
  - Can help meet increased calorie and protein needs.
  - Reduce episodes of aspiration pneumonia



# Other Steps

- Determine the cause if possible
- Talk to your neurologist
- See a gastroenterologist
- Meet with a registered dietitian



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# The Role of Physical and Occupational Therapy in Parkinson's Disease

Anne Mahnke, OTR/L  
Jennifer McKune, MPT

# What can Physical Therapy do?

- Physical therapy provides services to individuals and populations to develop, maintain and restore maximum movement and functional ability throughout the lifespan.
- This includes providing services in circumstances where movement and function are threatened by ageing, injury, pain, diseases, disorders, conditions or environmental factors.
- Functional movement is central to what it means to be healthy. (World Confederation for Physical Therapy, 2015)



# Goals of Physical Therapy:

- Promote quality of life and independence by encouraging activity and maximizing functional mobility
- Promote safety and fall prevention
- Improve movement for daily activities by recalibrating the body through large amplitude exercises
- Improve walking by incorporating large movement patterns and using internal and external cues



# What can Occupational therapy do?

- Dressing: pulling on/off clothes, buttoning, zippers, reaching feet/shoes
- Fine motor: cutting food and eating, hand-writing, opening containers, typing
- Mobility for Self Cares: getting in/out of bed, on/off of toilet, movements for bathing, cooking, and laundry
- Driving: addressing coordination, reaction time, and visual skills needed for safe driving



# Goals of Occupational Therapy:

- Increase independence with daily self cares through use of restorative or compensatory strategies
- Educate on how to implement aerobic training to achieve optimal benefit for management of Parkinson's symptoms
- Educate on high amplitude movements to increase ability to complete daily tasks.
- Improve coordination and strength for dressing, bathing, cooking, leisure activities, and work-related tasks
- Caregiver education





# Importance of Exercise to Manage Parkinson's Symptoms

"High-intensity exercise induces brain-protective effects that have the potential to not just slow down, but possibly reverse, the neurodegeneration associated with Parkinson's disease, a new pilot study suggests."

(Yale School of Medicine, 2023)

"The medications we have available are only for symptomatic treatment. They do not change the disease course. But exercise seems to go one step beyond and protect the brain at the neuronal level."

(Sule Tinaz, MD, PhD via Yale School of Medicine, 2023)



# Importance of Exercise with PD

- **Help Brain Cells Use Dopamine More Efficiently**
  - Exercise improves efficiency by modifying areas of the brain where dopamine signals are received (Substantia Nigra and Basal Ganglia)
- Exercise helps maintain old connections, form new ones, and restore lost ones
- Neuroplasticity = change in neural pathways and synapses due to changes in behavior, environment, neural processes, thinking, emotions (external and internal cues) (Fisher et al. 2004)
- Neuroplasticity from exercise outweighs the effects of neurodegeneration



# Working with Therapy

Working with a therapist can help increase confidence with exercise by developing a tailored exercise program, addressing any questions or concerns the patient or family may have, and promoting better compliance with the home exercise program.



# PT and OT Assessments:

## Standardized Testing:

- Strength and ROM
- Balance
- Gait
- Coordination (gross and fine motor)
- Functional performance
- Vision
- Cognition

Assessment and interventions are tailored to meet the needs of the individual. Goals are established to be meaningful and functional for each person.



# Early-stage Interventions

- Individualized exercise program
- LSVT-BIG and PWR! Moves – learned at diagnosis
- High Intensity Exercise
- Ask for referral upon diagnosis





# Early-stage Interventions:

- **Resistance Training.** Studies suggest muscular strength and functional gain are greater when high-intensity protocols are used involving primarily eccentric contraction (Dibble et al. 2006, Dibble et al. 2009)
  - Postural muscles
  - Trunk extensors
  - Hip extensors and hip abductors
  - Quadriceps and hamstrings
- **Aerobic Exercise**
  - Improves the effectiveness of levodopa, thus improving motor response
  - Produces a neuroprotective effect and helps to restore neuronal pathways impaired by PD (Fisher et al. 2004, Pothakos et al. 2009)



# Early-stage Interventions:

- **Balance Training**
  - Focus on postural control through exercises that incorporate somatosensory and musculoskeletal systems
- **Gait training.** External cue training (auditory, visual, and tactile) can improve walking speed, step length and freezing severity (Nieuwboer et al. 2007)
  - Treadmill training promotes a steady rate with regular and uniform speed through the generation of rhythmic gait cycles. This is viewed as an external cue to trigger the motor activity being performed (Nieuwboer et al. 2007)



# Early-stage Interventions:

- **Consistent.** Duration longer than 6 months showed gains on functional balance and mobility as compared to program of 2-10 weeks (National Parkinson Foundation)
- **Practice Movement Strategies**
  - Home exercise program
  - Attend classes in the community
  - Focus on reciprocal movement exercises
  - Use rhythmic and symmetric movements



# PD specific exercise programs

- LSVT BIG
- Parkinson's Wellness Recovery (PWR! Moves)

Using **large amplitude** movements at **high intensity** to increase dopamine output and counteract Parkinson's symptoms



# High Intensity Exercise

RPE SCALE	RATE OF PERCEIVED EXERTION
<b>10</b> /	<b>MAX EFFORT ACTIVITY</b> Feels almost impossible to keep going. Completely out of breath, unable to talk. Cannot maintain for more than a very short time
<b>9</b> /	<b>VERY HARD ACTIVITY</b> Very difficult to maintain exercise intensity. Can barely breathe and speak only a few words
<b>7-8</b> /	<b>VIGOROUS ACTIVITY</b> Borderline uncomfortable. Short of breath, can speak a sentence
<b>4-6</b> /	<b>MODERATE ACTIVITY</b> Breathing heavily, can hold a short conversation. Still somewhat comfortable, but becoming noticeably more challenging
<b>2-3</b> /	<b>LIGHT ACTIVITY</b> Feels like you can maintain for hours. Easy to breathe and carry a conversation
<b>1</b> /	<b>VERY LIGHT ACTIVITY</b> Hardly any exertion, but more than sleeping, watching TV, etc





# High Intensity Exercise

## Heartrate:

Vigorous Physical Activity defined as 70-85% of HR max

Max Heartrate =  $220 - \text{age}$

Calculate the 70-85% range for each patient

## Sustained activity vs. High intensity interval training



# Middle-stage Therapy Interventions

LSVT-BIG and PWR! Moves (can be modified to meet individual abilities)

ADL specific interventions

Adaptive equipment

- Consider use of a cane, rollator walker, U-Step walker



# Middle-Stage Therapy Interventions

## Cueing for Parkinson's Disease:

- The goal of therapy is often to help patients develop intrinsic cues needed to succeed in any environment. However, in mid and late stages of PD, extrinsic cues may be needed for safety and success.
- **Extrinsic Cueing**
  - Visual cues
  - Auditory cues
- **Intrinsic Cueing**
  - Positive attitude and mindset—the “I can.” and “I will.”
  - Mental rehearsal of difficult or new tasks
  - Internal dialogue—end goal of LSVT BIG to “Think BIG”
  - Visualization of tasks such as turning without freezing

(Ebersbach et al. 2010 2014, Farley & Koshland 2005, Tamir et al. 2007)



# Middle-Stage Therapy Interventions

- **PD Specific Exercise Education:**
  - Modifications to HEP
  - Proprioceptive work
- **Gait and Balance Training:**
  - Fall prevention and recovery
  - Home safety assessment
  - Assistive devices
  - Vision
  - Blood pressure fluctuations
- **Strength Training:**
  - Proximal strength during ADLs/Work
  - Cognitive dual task
- **Cardiovascular:**
  - Endurance training
  - Pacing
- **Fine motor training:**
  - Training for different types of grasp
- **ADL Training:**
  - Driving
  - Home modifications
  - Sleep hygiene
  - Adaptive device trials
- **Work Task Training:**
  - Workstation ergonomics
  - Adaptive devices



# Late-Stage Therapy Interventions

- Maximize Comfort, Dignity, and quality of life
- Exercises with modifications
  - Increased stretching
  - Chair exercises
  - Care giver assistance
- Re-addressing **safe** living situations
  - Level of supervision
  - Home setup
  - Hired caregivers
  - Placement
- AE/DME evaluation
  - Wheelchair (manual, power, seating systems, etc.)
  - Home AE/DME (reacher, tub transfer bench, commode, lift, etc.)
  - Home modifications (grab bars, doorways, visual cues, etc.)





# Late-Stage Therapy Interventions

- Awareness of posture and positioning
  - Appropriate cushions/seating systems
  - Frequent position changes
    - Weight shifts/Stretching
    - Transfers
    - Wheelchair options
- Safe transfers and bed mobility
  - Safety for the patient and care giver!
  - Body mechanics
  - Equipment recommendations as needed
- Caregiver support
  - Prevention of injury
  - Prevention of burnout
  - Support groups



# When to get a referral to PT/OT:

- A new diagnosis of Parkinson's to learn appropriate exercises in order to maintain function and mobility
- Decreased mobility
- Increased difficulty with daily activities



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World Confederation for Physical Therapy, 2015







# The Role of Speech- Language Pathologists in Parkinson's Disease

Natalie Smith, MA, CCC-SLP  
University of Nebraska Medical Center

# Objectives

- Introduction
- What can Parkinson's affect?
- How to identify functional changes relating to Speech Therapy
- How to treat those changes through therapy
- Conclusion
- References

# What Does a Speech Therapist Do?



# Speech-Language Pathologist (SLP)



---

An SLP works with clients along the entire spectrum of life.

---



Often, an SLP will assess and treat clients with Parkinson's Disease (PD).



# What Do We Target?



---

**Speech**: how your speech sounds (clear vs. mumbled or slurred; fast vs. slow; stuttered)

---

**Language**: effectively forming thoughts into sentences, word finding, comprehension (understanding others)

---

**Cognition**: memory, problem solving, safety awareness, executive functioning, organization, attention, impulse control

---

**Voicing**: how does your voice sound (loud vs. quiet, strong vs. weak, clear vs. hoarse/raspy/breathy)

---

**Swallowing**: safe consumption of solids, liquids and pills while using safe swallowing strategies

---



# Parkinson's Disease and Speech and Voicing

How might PD impact the speech and vocal system?

# PD and Speech and Voicing



YOUR VOICE MAY SOUND  
"NORMAL" OR "THE SAME"  
BUT MIGHT SOUND QUIET OR  
MUMBLED TO FRIENDS AND  
FAMILY.



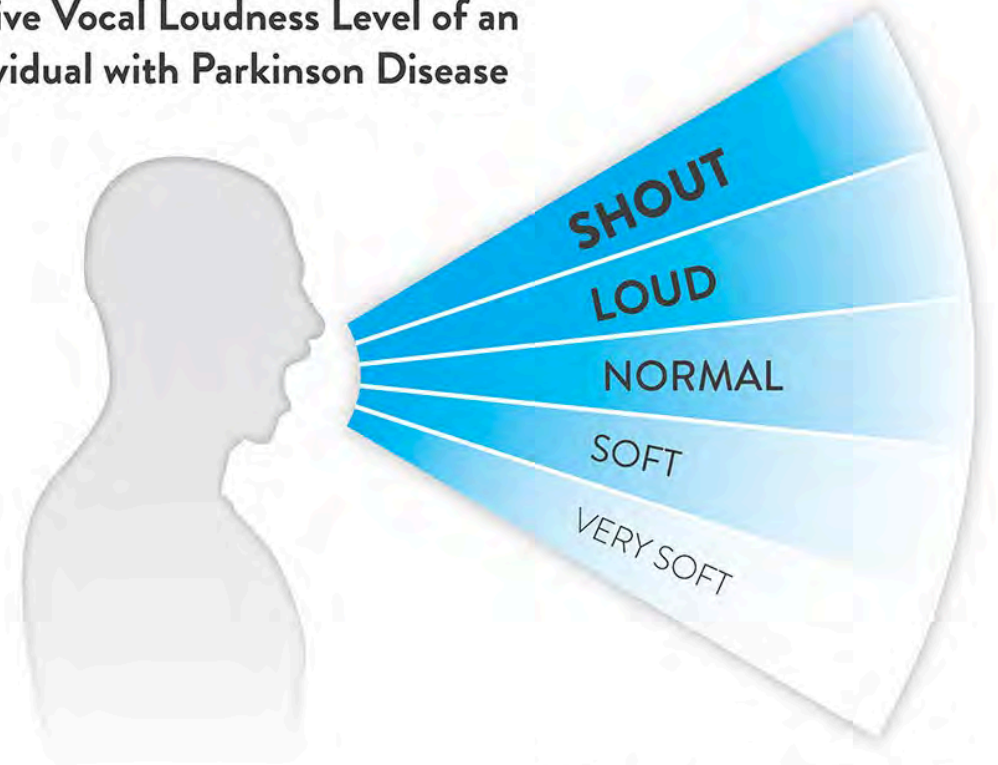
YOU MIGHT FEEL LIKE YOU ARE  
SHOUTING WHEN REALLY YOU  
ARE SPEAKING AT A MORE  
APPROPRIATE VOLUME FOR  
CONVERSATION (~65-70 DB).

# PD and Speech and Voicing

Commonly Reported Speech and Voicing Issues:

- Soft Voice
- Hoarseness/Raspiness
- Monotone
- Mumbled/Slurred Speech
- Rapid, Slow or Varied Speaking Rate
- Breathlessness


Relative Vocal Loudness Level of an Individual with Parkinson Disease



As a result of Parkinson disease you will need to use more vocal effort to have a voice within normal loudness limits.

(Adapted from Carolyn Mead Bonitati, 1987)

# PD and Speech and Voicing: What to look for.



**Voice Handicap Index (VHI-10)**

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Instructions: These are statements that many people have used to describe their voices and effects of their voices on their lives. Circle the response that indicates how frequently you have the same experience.

0 = never    1 = almost never    2 = sometimes    3 = almost always    4 = always

1. My voice makes it difficult for people to hear me.	0	1	2	3	4
2. I run out of air when I talk.	0	1	2	3	4
3. People have difficulty understanding me in a noisy room.	0	1	2	3	4
4. The sound of my voice varies throughout the day.	0	1	2	3	4
5. My family has difficulty hearing me when I call them throughout the house.	0	1	2	3	4
6. I use the phone less often than I would like to.	0	1	2	3	4
7. I'm tense when talking to others because of my voice.	0	1	2	3	4
8. I tend to avoid groups of people because of my voice.	0	1	2	3	4
9. People seem irritated with my voice.	0	1	2	3	4
10. People ask, "What's wrong with your voice?"	0	1	2	3	4

Roam, C. Lee, A. Ostrows, J. Dolko, T. and Murray, T. (2004). Development and Validation of the Voice Handicap Index-10. *Laryngoscope* 114(9): 1849-1858

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226 S. Wenden Hill Rd., 1027 West Chesterfield, MO 63077 • phone 314-823-8200 • fax 314-834-3710  
Website: [www.southwesthealthservices.com](http://www.southwesthealthservices.com)

My voice makes it difficult for people to hear me.

People have difficulty understanding me in a noisy room.

My voice issues limit my personal and social life.

I feel left out of conversations because of my voice.

I cannot participate in telephone calls because of my voice.



# PD and Speech and Voicing: What to look for.

My voice problem causes me to lose income.

I have to strain to project my voice.

My voice clarity is unpredictable.

My voice problem upsets me.

My voice makes me feel handicapped.

People ask, "What's wrong with your voice?"

**THE VOICE & SWALLOWING CENTER**  
A Division of State Health Services, PC

**Voice Handicap Index (VHI-10)**

Name: \_\_\_\_\_ Date: \_\_\_\_\_

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10. People ask, "What's wrong with your voice?"     1    2    3    4

Down, G. Lee, A. Osborne, J. Sello, T. and Murray, T (2004). Development and Validation of the Voice Handicap Index-10. *Laryngoscope* 114(9): 1349-1356

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228 S Woods Mill Rd., #27 West Chesterfield, MO 63397 • phone 314-523-8200 • fax 314-434-2191  
Website: [www.southahealthservices.com](http://www.southahealthservices.com)

# Voice Treatment Options

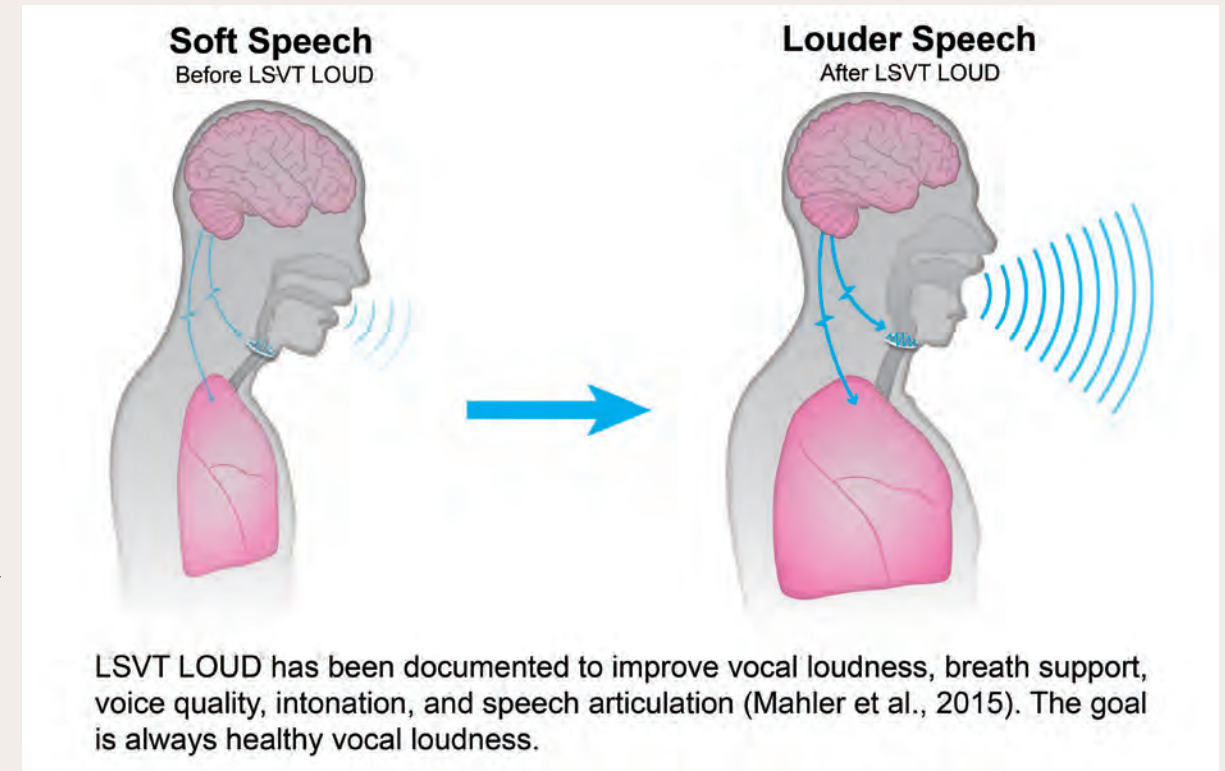
- LSVT LOUD
- SPEAK OUT!
- PhoRTE
- Traditional Speech Therapy

# LSVT LOUD: LSVT Global

“LSVT LOUD is an effective speech treatment for people with Parkinson’s Disease and other neurological conditions.”

## Speak LOUD.

This treatment method is aimed at helping people recalibrate their perceptions of their voice, so they know how loud or soft they sound to other people and to feel more comfortable using a stronger voice at a more typical loudness level.



# LSVT LOUD

## Treatment Plan:

4x/week for 4  
weeks (16  
sessions)

1-hour long  
sessions

Includes daily  
homework and  
carryover exercises

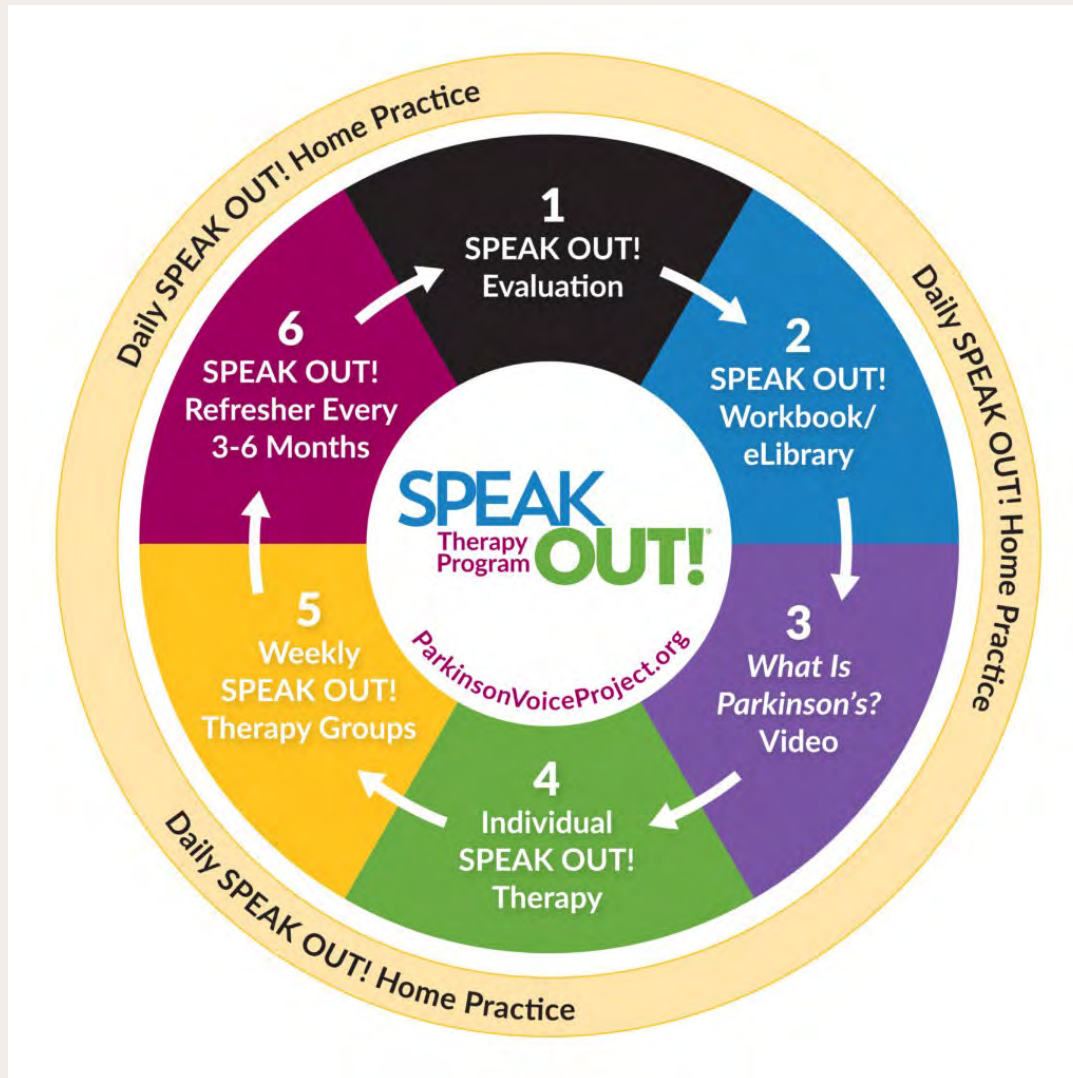
## After Discharge:

Continue practicing once a day for 10-15 minutes

### Other Resources:

- LOUD for LIFE: Community-based exercise class for graduates of the LSVT LOUD program to practice their exercises in a group session.
- Tune-up Sessions: Stay in touch with the clinician for regular check-ups and short bouts of therapy to keep your voice strong.
- LSVT Coach: Speech exercise computer program to practice exercises while it provides results and feedback.
- LSVT LOUD Homework Helper Videos.

# SPEAK OUT!: Parkinson's Voice Project



“To help people with Parkinson’s and related neurological disorders regain and retain their speech and swallowing.”

## Speak with INTENT.

This program combines: education, individual and group speech therapy, daily home practice and continuous follow-ups.



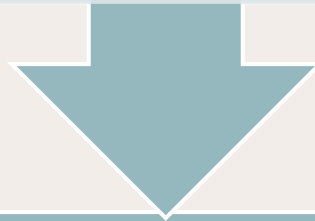
# SPEAK OUT!

## Treatment Plan:

2-3x/week for 4 weeks  
(8-12 sessions)

30—40-minute long  
sessions

Daily homework: 2x/day  
during treatment, 1x/day  
after graduation



## After Discharge:

Continue practicing your exercises once a day.  
SPEAK OUT! Refresher: every 3-6 months.

### Other Resources:

- Online SPEAK OUT! Home Practice Sessions: Monday-Friday. Free sessions provided to practice your daily exercises.
- SPEAK OUT! Workbook and Flashcards
- E-Library
- Parkinson's Sing-Alongs via Zoom



# PhoRTE: Phonation Resistance Training Exercises

“Voice therapy for pathologic age-related voice changes that occur in older adults”.

Uses high-intensity vocal exercise to systematically rehabilitate the vocal mechanism and improve vocal endurance.



## Treatment Plan:

1x/week x4-8 weeks completing 5 vocal tasks

1-hour long sessions

Home Practice: 12-15 minutes, 6 days/week



# Traditional Speech Therapy

- May be beneficial if:
  - Unable to locate a certified provider near your home.
  - Time constraints - you are unable to attend therapy multiple times a week.
  - Transportation issues.
- Can be very beneficial if working on a variety of concerns, such as voicing, speech and cognition.

# Parkinson's Disease and Swallowing

How might PD impact swallowing safety?

# Swallowing Difficulties – Common Symptoms

- Globus sensation: feeling like something is stuck in your throat.
- Throat Clearing
- Coughing
- Watery eyes/runny nose during mealtimes
- Weak Cough
- Drooling
- Prolonged chewing/difficulty chewing certain foods
- Pocketing
- Longer mealtimes
- Difficulty swallowing pills, liquids or solids
- Unexpected weight loss



# Dysphagia Can Lead To...



- Malnutrition
- Weight loss
- Dehydration
- Aspiration: when food/liquid “goes down the wrong pipe”
- Silent: you do not cough or throat clear when aspiration occurs
  - Occurs in ~20% of people with PD
- Significant risk of aspiration pneumonia in people with PD

# Assessment of Swallowing Difficulties (Dysphagia)

1. Clinical Swallow Evaluation
2. Modified Barium Swallow Study (MBSS)
3. Fiberoptic Endoscopic Evaluation of Swallowing (FEES)



# Clinical Swallow Evaluation

*Eating Assessment Tool (EAT-10)*  
*Circle the appropriate response*

To what extent are the following scenarios problematic for you?	0 = No problem 4 = Severe problem				
1. My swallowing problem has caused me to lose weight.	0	1	2	3	4
2. My swallowing problem interferes with my ability to go out for meals.	0	1	2	3	4
3. Swallowing liquids takes extra effort.	0	1	2	3	4
4. Swallowing solids takes extra effort.	0	1	2	3	4
5. Swallowing pills takes extra effort.	0	1	2	3	4
6. Swallowing is painful.	0	1	2	3	4
7. The pleasure of eating is affected by my swallowing.	0	1	2	3	4
8. When I swallow food sticks in my throat.	0	1	2	3	4
9. I cough when I eat.	0	1	2	3	4
10. Swallowing is stressful.	0	1	2	3	4
Total EAT-10					

Qualitative questionnaires

- EAT-10

Oral Mechanism Exam

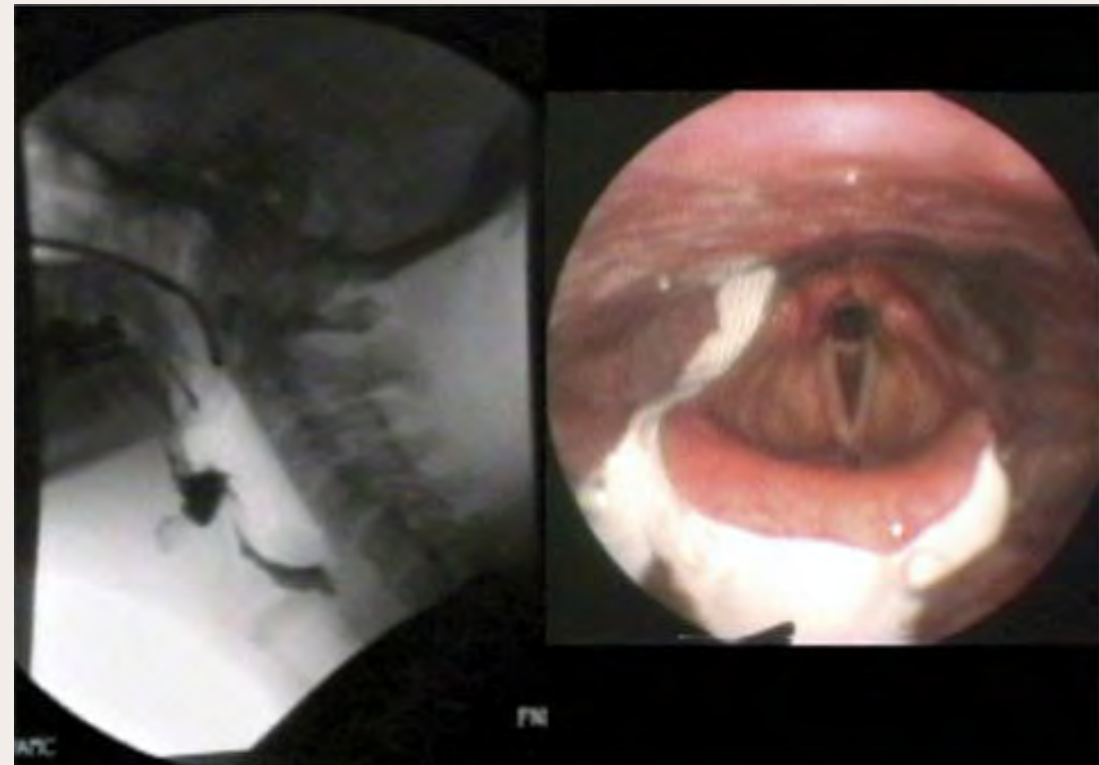
PO trials of different textures and consistencies

Refer for instrumental assessment

# MBSS vs. FEES

**Table 5**  
**Advantages and disadvantages**

	MBS	FEES
Advantages	<ul style="list-style-type: none"> <li>Noninvasive</li> <li>Evaluates oral, pharyngeal, and esophageal phases of the swallow</li> <li>Visualization of cervical hardware after spinal surgery or cervical osteophytes</li> <li>Evaluation of hyolaryngeal elevation</li> </ul>	<ul style="list-style-type: none"> <li>Provides direct view of anatomy structures to evaluate laryngeal and pharyngeal structures</li> <li>May be performed at bedside</li> <li>Uses real food and liquid</li> <li>Examination can last throughout a meal to evaluate for fatigue if needed</li> </ul>
Disadvantages	<ul style="list-style-type: none"> <li>Radiation exposure so examination time may be limited</li> <li>Fluoroscopy unit is turned off between bolus presentations so possible to miss salient event if not imaging between swallows</li> <li>Examination usually requires transportation to radiology department or mobile unit</li> </ul>	<ul style="list-style-type: none"> <li>Whiteout period during height of swallow</li> <li>Examiner must make inferences regarding laryngeal penetration or aspiration during the swallow</li> <li>Time and expense involved with decontamination of endoscope</li> </ul>



# How to Treat Dysphagia

## The IDDSI Framework

Providing a common terminology for describing food textures and drink thicknesses to improve safety for individuals with swallowing difficulties.



© The International Dysphagia Diet Standardisation Initiative 2019 @ <https://iddsi.org/framework/>  
Licensed under the Creative Commons Attribution on Sharealike 4.0 License <https://creativecommons.org/licenses/by-sa/4.0/legalcode>.  
Derivative works extending beyond language translation are NOT PERMITTED.

---

Participate in speech therapy to improve strength and coordination of the swallow.

---

Expiratory Muscle Strength Training: improving respiratory muscle strength to treat dysphagia and dysphonia (voice).

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Diet Modifications.

---

Using safe swallowing strategies.



# Dysphagia Exercises

- May strengthen the oral phase
  - Chewing, coordination, safe management of solids/liquids
- May strengthen the pharyngeal phase
  - Hard and fast swallows, clearing “residuals”, airway protection
- Bolus-driven therapy



# Expiratory Muscle Strength Training (EMST)

The Breather



- Improves cough strength and clearance of any solids/liquids in the throat.
- Improves the movement and strength of the swallowing muscles to move solids/liquids through the throat.
- It helps elevate the larynx during the swallow, which also helps with airway protection.
- This may also help improve your volume!



EMST-150

# Diet Modifications: Alterations to the consistency of solids and liquids to make eating and drinking easier and safer.



## Solids:

- Regular
- Soft and bite-sized
- Minced and moist
- Pureed

## Liquids:

- Thin
- Slightly Thick
- Mildly Thick
- Moderately Thick

# Safe Swallowing Strategies

1. Small sips and bites.
2. Eat slowly.
3. Maintain good posture.
4. Effortful Swallows.
5. Alternate solids/liquids every 2-3 bites.
6. Double swallow as needed.
7. Throat clear and swallow as needed.
8. Take rest breaks as needed.





# Aspiration Precautions

- Sit upright at a 90-degree angle when eating and drinking.
- Remain upright at least 45 degrees for 30-60 minutes after eating.
- Cut food into small, manageable pieces.
- Take your time! Your food will not run away from you!
- Minimize distractions when eating and drinking, such as watching the tv or talking to someone.





# Signs and Symptoms of Aspiration



- Throat Clearing
- Coughing
- Choking
- Runny nose
- Watery eyes
- Trouble breathing
- Wheezing

# Final tips & takeaways

- If you notice any changes from your baseline, inform your physician and other healthcare workers (therapists, counselors, etc.).
- If you have previously participated in therapy and notice some of your symptoms are progressing, it may be time for a refresher!
- Try to stay as mentally and physically active each day and be aware of your limits which may impact your safety.
- It is better to target any problems that may arise sooner rather than later to try and maintain your strength and independence!

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Thank  
you!

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# Question and Answer With the Experts

**Amy Hellman, MD**

**Kiel Woodward, MD**

Parkinsons Disease Symposium, 2024



University of Nebraska  
Medical Center™



# Frequently Asked Questions



# Frequently Asked Questions

## Is carbidopa/levodopa still the treatment of choice?

- There are many different types of treatments for Parkinsons Disease
- While levodopa may be one of the oldest, it is still the most effective medication!
- Treatment is tailored to the individual





# Frequently Asked Questions

## How do I know when I need to start using carbidopa/levodopa?

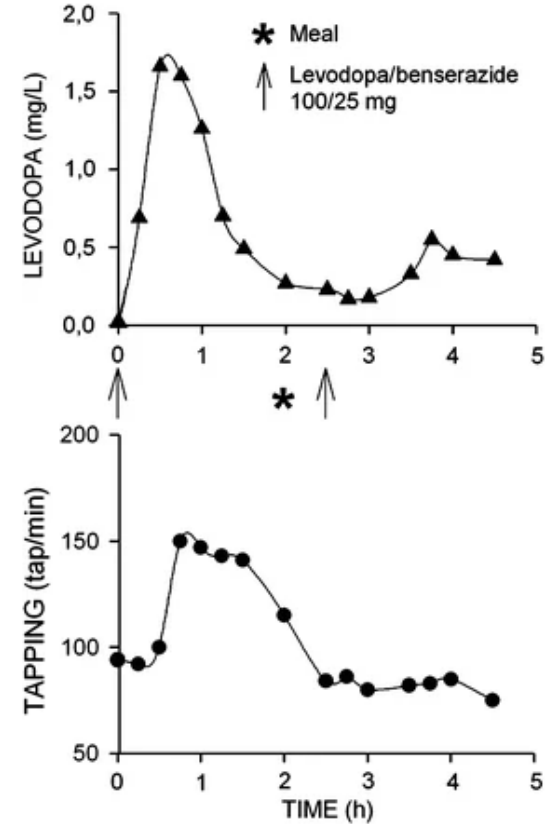
- Discuss with your doctor
- Things to consider
  - Severity of symptoms
  - Ability to function and stay physically active
  - Quality of life



# Frequently Asked Questions

How important is it to take carbidopa/levodopa on an empty stomach?

- For some, VERY. For others, NOT AT ALL
- Levodopa competes with some proteins for absorption from the gut, sometimes reducing effectiveness if taken simultaneously
- Some people find increased benefit when taking either 30 minutes before or 1-2 hours following a protein-rich meal







# Frequently Asked Questions

How can I best track ON and OFF times (motor fluctuations) to see if I need a medication adjustment?

- Many ways! Whatever is easiest for you
  - Good old pen and paper charts
    - A free template can be found at [Parkinson.org](http://Parkinson.org)
    - Example shown on the next slide
  - Multiple cell phone apps
    - "Parkinson Symptom Tracking"
    - "ADPA Symptom Tracker"
    - "Parkinson's Disease Manager"

# Symptoms Log Example

TIME	MEDICATION	MEAL	SLEEP
5:00 am			
5:30 am			
6:00 am			
6:30 am			
7:00 am			
7:30 am			
8:00 am			
8:30 am			
9:00 am			
9:30 am			
10:00 am			
10:30 am			
11:00 am			
11:30 am			

List the symptoms you want to track - e.g., tremor, dyskinesia, anxiety - in the top row.  
 When those symptoms occur, fill in the number that corresponds to the severity at that time.  
 Write medication names and doses next to the times at which the person with Parkinson's takes them.

Put an X (or list foods) in the "Meal" column at mealtimes.

Put an X in the "Sleep" column when the person with Parkinson's sleeps.

0 = NONE

1 = SLIGHT OR MILD

2 = MODERATE, BOTHERSOME

3 = SEVERE, VERY BOTHERSOME

SYMPTOMS List 3			NOTES
0 1 2 3	0 1 2 3	0 1 2 3	
0 1 2 3	0 1 2 3	0 1 2 3	
0 1 2 3	0 1 2 3	0 1 2 3	
0 1 2 3	0 1 2 3	0 1 2 3	
0 1 2 3	0 1 2 3	0 1 2 3	
0 1 2 3	0 1 2 3	0 1 2 3	
0 1 2 3	0 1 2 3	0 1 2 3	
0 1 2 3	0 1 2 3	0 1 2 3	
0 1 2 3	0 1 2 3	0 1 2 3	
0 1 2 3	0 1 2 3	0 1 2 3	
0 1 2 3	0 1 2 3	0 1 2 3	
0 1 2 3	0 1 2 3	0 1 2 3	
0 1 2 3	0 1 2 3	0 1 2 3	
0 1 2 3	0 1 2 3	0 1 2 3	



# Frequently Asked Questions

How does THC and/or CBD affect PD?

- Proposition 437 recently passed in a landslide approval for use of medical marijuana in Nebraska
- Benefit for PD motor symptoms is anecdotal only. Clinical trials do not show consistent evidence of improvement
- Side effects include cognitive impairment, dizziness, fatigue, dependence



# Frequently Asked Questions

## Is there a link between diabetes and PD?

- Yes. Multiple large studies suggest an increased risk of developing PD by 30% in those with longstanding diabetes (>10 years)
  - Also evidence of increased risk for other neurodegenerative diseases (e.g., Alzheimers)
- Proposed cause: Insulin resistance, high blood sugars cause oxidative damage, chronic neuron inflammation and dysfunction
- Certain diabetes treatments are being investigated for neuroprotective benefits in Parkinsons Disease
  - Multiple GLP-1 agonists and DPP4 inhibitors

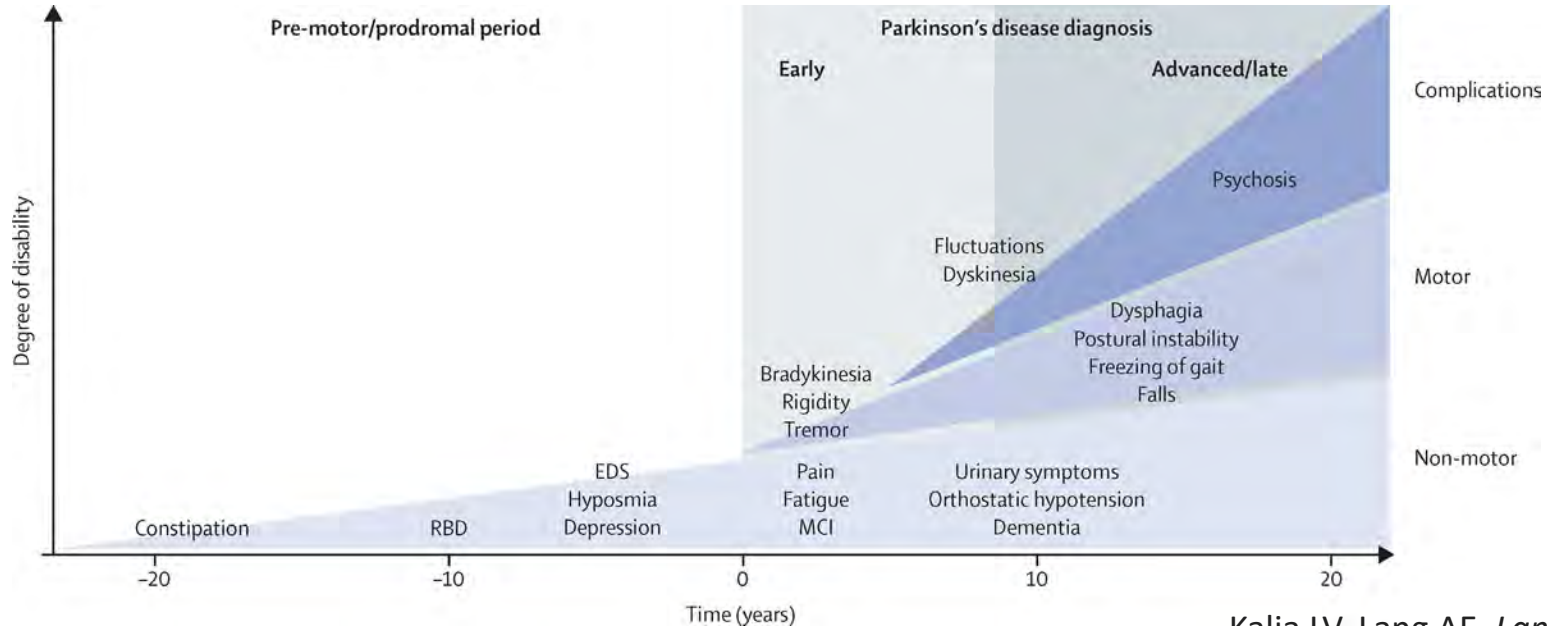




# Frequently Asked Questions

## How long before motor symptoms can one have PD?

- Non-motor symptoms can be present up to 20-30 years beforehand!



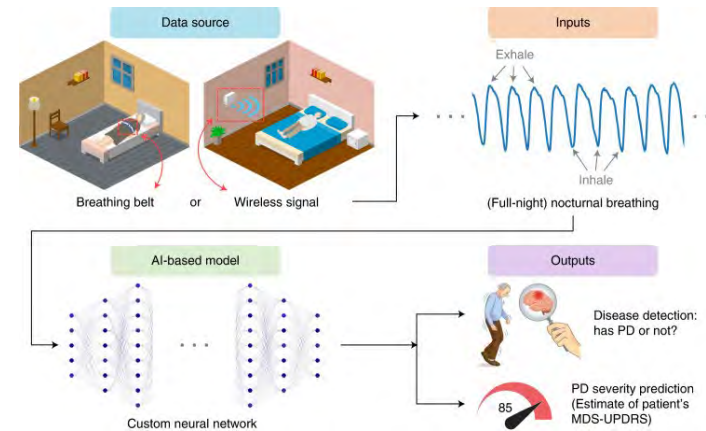




# Frequently Asked Questions

## Is Artificial Intelligence (AI) playing a role in the clinical treatment of Parkinsons Disease?

- Being developed for early diagnosis, tracking disease progression, and helping identifying targets for disease modifying therapies
- No practical clinical application yet





# Frequently Asked Questions

**Is DBS only good for tremors, or for other PD symptoms, as well?**

- Rule-of-thumb: DBS treats all symptoms of Parkinsons Disease that are also treated by levodopa
  - Exception: can treat tremor and dystonia better than levodopa
- Three main indications for DBS in PD:
  - Levodopa helps, but there are severe motor fluctuations despite optimal adjustments to medications
  - Levodopa helps, but experience limiting side effects
  - Levodopa helps, but with refractory tremor

# Frequently Asked Questions

**I have toes curling in one foot compared to the other that is painful and makes walking difficult, is this common?**

- Yes! Parkinsons Disease is sometimes accompanied by a symptom called "dystonia"
- Dystonia is overactivity of muscles causing abnormal posturing and sometimes pain
- Most commonly toe curling or ankle twisting, but can involve hands, arms, the body, neck or face!
- Sometimes related to dosing of levodopa

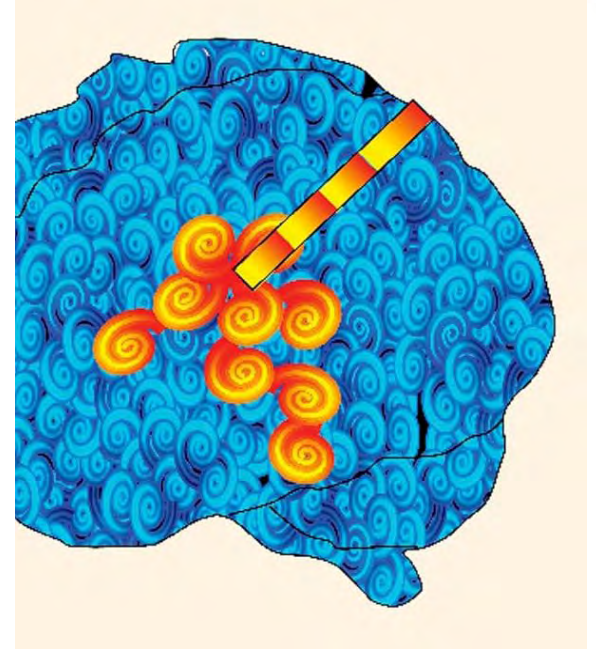




# Frequently Asked Questions

## How do you know how to adjust DBS settings?

- Same as medications! Based on symptoms and exam, ability to function
- Goal is to have satisfactory control of symptoms at the lowest possible settings to avoid side effects and preserve battery life



# Frequently Asked Questions

## Can DBS be used to reduce anxiety or other mood symptoms due to PD and medications?

- Not directly – but by reducing motor fluctuations and reducing medication burden, it often alleviates anxiety that is associated with these problems
- Severe, refractory Obsessive-Compulsive Disorder (OCD), a subtype of anxiety, is approved for treatment by DBS. But by stimulating a different part of the brain than PD
- Other anxiety treatment with DBS is experimental







# Frequently Asked Questions

## Is there anything that can be done to combat fatigue?

- Optimize the quality of your sleep – sleep hygiene
- Minimize other causes of fatigue
  - Address underlying sleep disorders
  - Screen for nutritional/hormonal abnormalities
  - Reduce medication burden, as able
- Take naps when needed

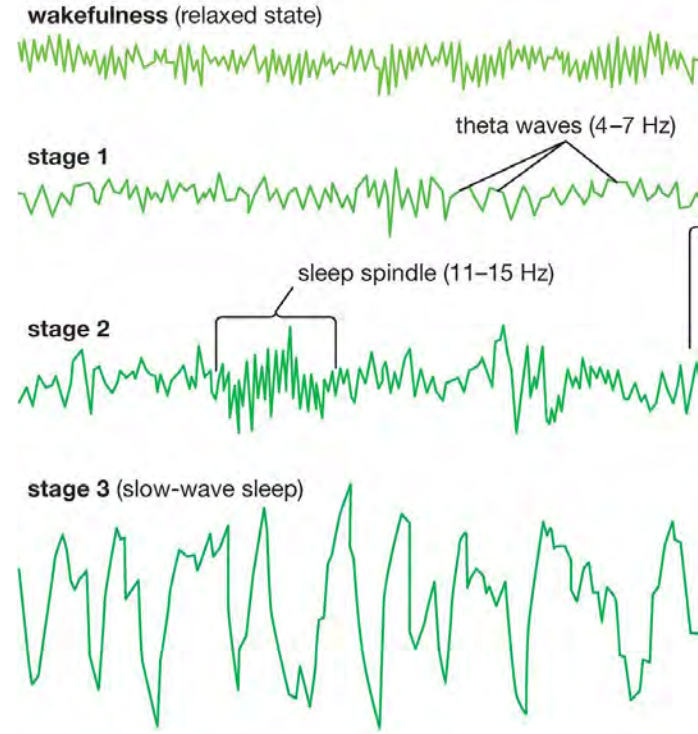




# Frequently Asked Questions

## Why do tremors stop during sleep?

- Almost all involuntary movements stop during sleep!
- The exact reasons are not known for certain, but the following likely contribute:
  - Reduced activity of motor control centers
  - Generalized slowing of brain activity
  - Increased levels of inhibitory/relaxing neurotransmitters
  - Decreased levels of excitatory neurotransmitters



Example of typical EEG tracings during wakefulness and sleep



# Frequently Asked Questions

## Any updates to the Leukine clinical trial with Dr. Gendelman?

- Completed a 33-month [2013-2016] phase I trial of safety and tolerability of Leukine (sargramostim) in PD patients
- Eventual goal of study is to determine if modulation of the immune system can slow progression of PD and other neurodegenerative diseases
- 5 patients completed the study without serious adverse events clearly attributable to the study drug
- A second, 48-week open-label phase I trial was just completed with 11 subjects earlier this month. Goals of study are safety/tolerability and immune system biomarker analysis. Results not yet published
- Considering phase II trial to determine efficacy for PD symptoms at some point in the future





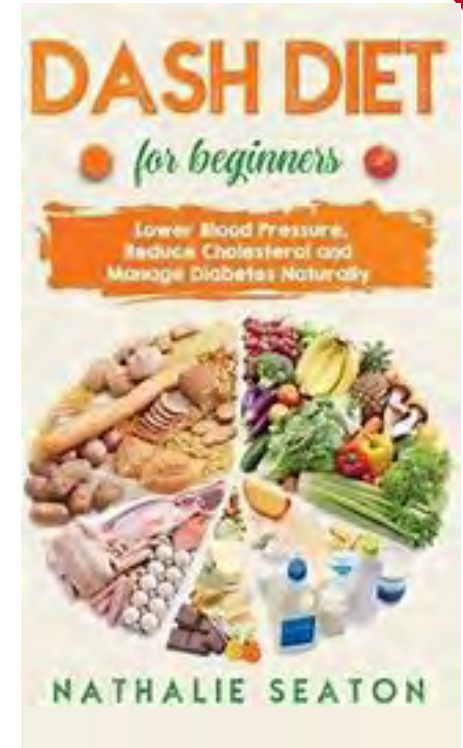
# Frequently Asked Questions

**Will eating certain foods/nutrients help produce more dopamine in my body?**

- Unfortunately, no

**Any nutritional suggestions to improve gut-brain health?**

- Mediterranean/DASH diet

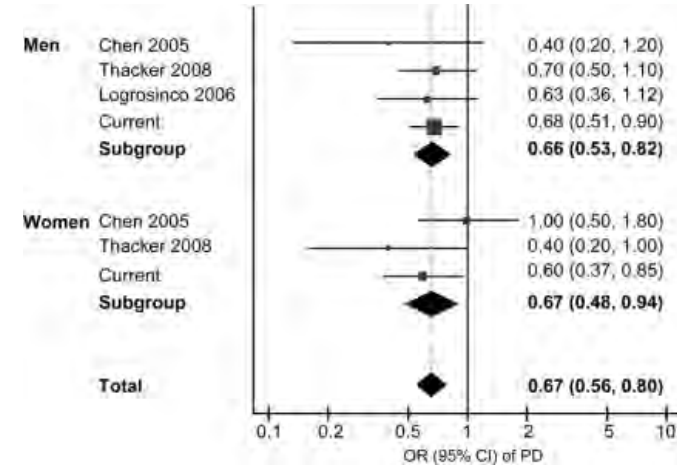




# Frequently Asked Questions

## What can be done to slow the progression of PD?

- EXERCISE!
- Regular physical activity has been shown to exert a neuroprotective effect, improving motor symptoms and cognition
- Regular, vigorous aerobic exercise starting in midlife has been shown to reduce risk of developing Parkinsons Disease by up to 33%



Xu Q, et al. Neurology. 2010

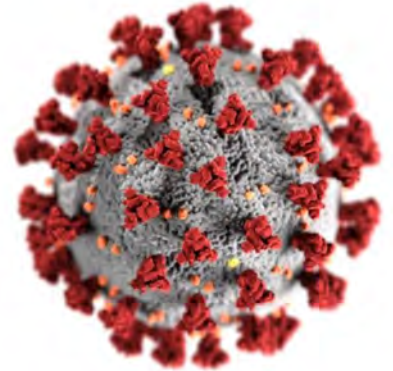




# Frequently Asked Questions

## Has COVID been associated with increased risk of developing PD?

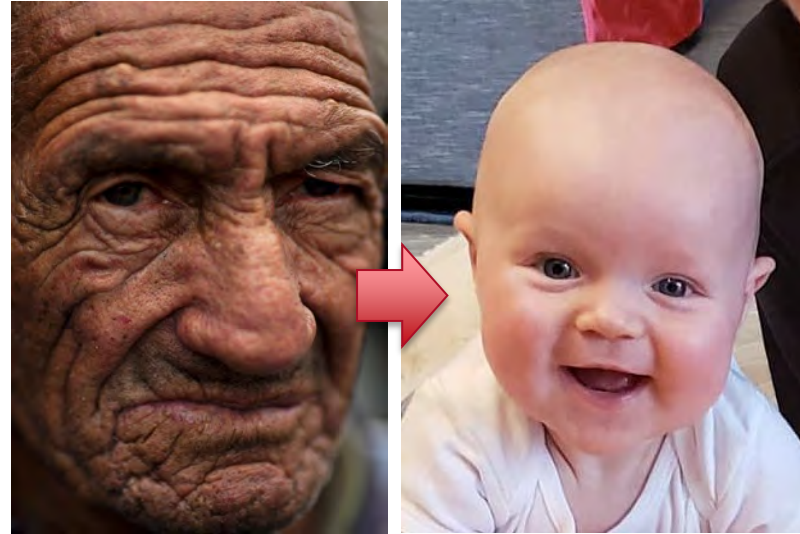
- Not yet...
- But, since COVID-19 remains a new illness, and PD is known to be a disease that develops slowly over years, *the relationship between them may yet unfold over time*
- Vaccination against COVID is recommended, as motor and cognitive symptoms are exacerbated during an infection and recovery



# Frequently Asked Questions

## Does Botox treat PD?

- Yes, Botox can be very effective at treating certain symptoms of PD refractory to medications
  - Dystonia
  - Bothersome drooling
  - Overactive bladder (urgency incontinence)
- Can also treat:
  - Chronic migraine headaches
  - Excessive sweating
  - And wrinkles!



Before Botox

After Botox



# Frequently Asked Questions

## Does Parkinson's Disease cause pain or arthritis?

- Reduced movement from rigidity and akinesia can lead to musculoskeletal pain
- Dystonia caused by PD can be painful
- Changes in posture can lead to pinched nerves
- Less commonly, nerve endings can be damaged (neuropathy)
- Occasionally "central pain" – can be an ill-defined, boring pain in certain areas or all-over



# Frequently Asked Questions

## What is dementia's impact on the expected duration of the disease?

- Dementia does not directly impact duration of disease, it is a symptom of the underlying disease
- Impulsivity and impaired attention can increase accidents [e.g., falls, aspiration, medication mismanagement] that can lead to increased mortality
- Presence of dementia reduces lifespan by roughly 1-2 years compared to those without. Highly variable!



# Frequently Asked Questions

What are signs of Dementia with Lewy Bodies? What can be expected?



- Lewy Body Dementia Support and Wellness Group (patients and caregivers)
  - 3rd Monday of each month, 9:30am-11am at Heartland Neurological Therapy and Wellness Center
  - Julie Pavekla, APRN [jupavelka@nebraskamed.com](mailto:jupavelka@nebraskamed.com)
- Lewy Body Dementia Caregiver Support Group
  - Zoom every 4th Friday from 1pm-2pm
  - Dawn Franklin, RN [dfranklin@nebraskamed.com](mailto:dfranklin@nebraskamed.com).



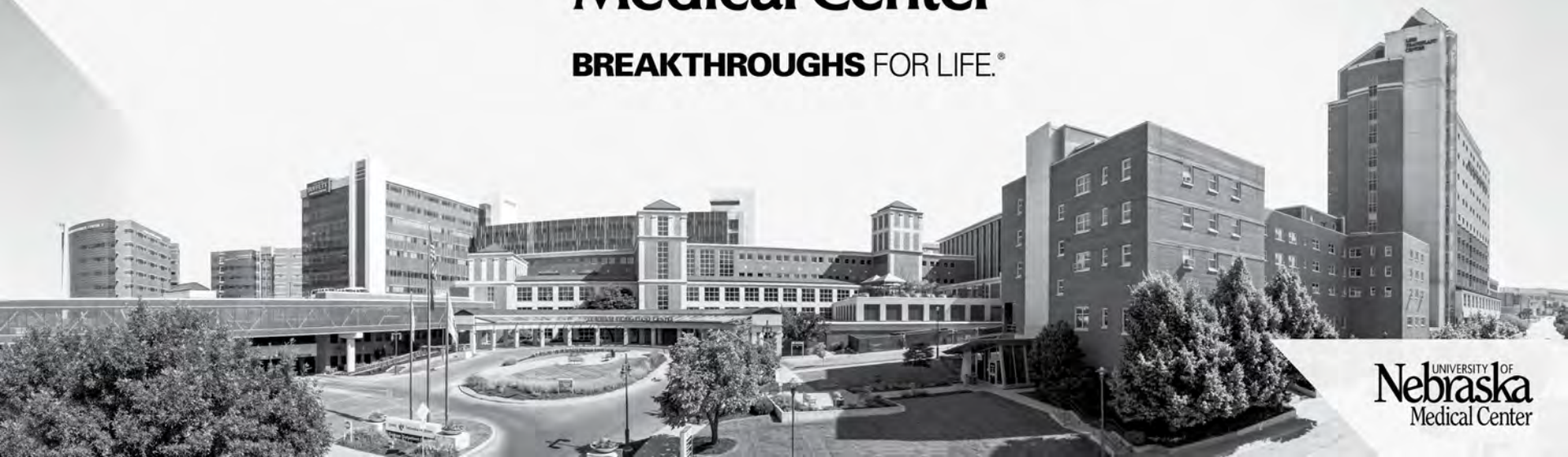


**Thank you for coming!**



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