

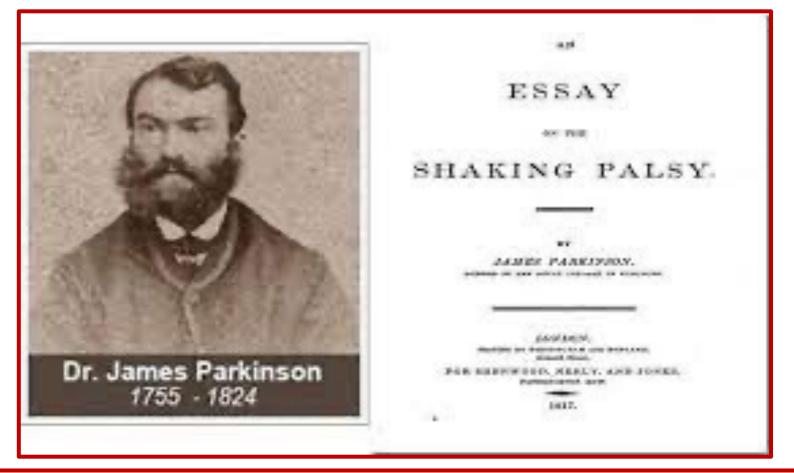






Parkinson's Disease: An Insider's View Barry Centini, PhD

January 24, 2023



One of the most prevalent <u>neurodegenerative</u> diseases worldwide is still referred to as 'Parkinson's disease'. The condition is named after James Parkinson who, in <u>1817</u>, described the shaking palsy (paralysis agitans).

THROUGHOUT THIS PRESENTATION

PD

STANDS FOR PARKINSON'S DISEASE

AGENDA

- ✓ WHY AM I HERE?
- ✓ WHERE DID I GET MY INFORMATION?
- ✓ WHAT IS PARKINSONISM?
- ✓ WHAT IS PARKINSON'S DISEASE?
- ✓ MY JOURNEY SO FAR
- ✓ GREENSPRING SUPPORT
- ✓ FUTURE HOPES
- ✓ Q&A



Emo Philips

"I used to think that the brain was the most wonderful organ in my body.

Then I realized who was telling me this."

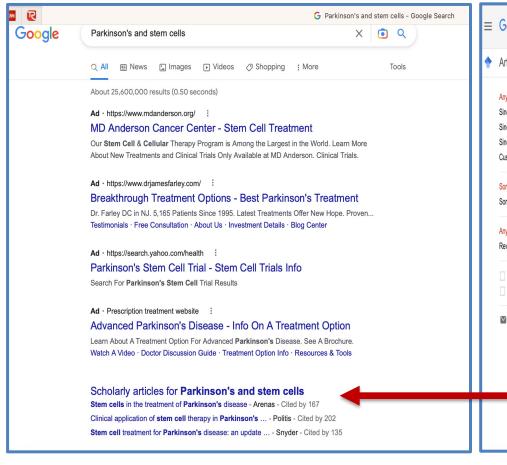
PD is not an infectious virus or bacteria. It is a breakdown of some brain functions, namely those that produce and process dopamine.

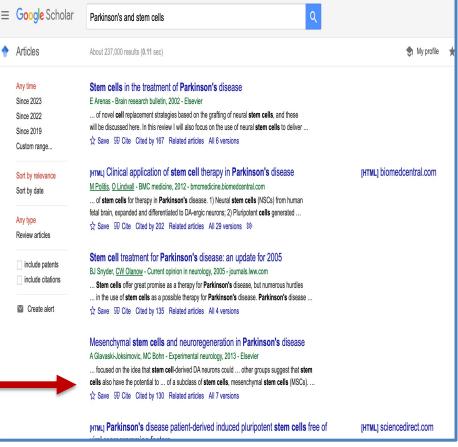
The irony is: I will be describing my brain malfunctions using a partially malfunctioning brain!

Where did I get my information?

- 1. My neurologist Dr. Nicole Dietz
- 2. Fellow Greensping PD Patients
- 3. Some Google
- 4. More Google Scholar









Say that three times!!

What is parkinsonism? Parkinsonism is an umbrella term that refers to brain conditions that cause slowed movements, rigidity (stiffness) and tremors. These conditions can happen for many reasons, including genetic mutations, reactions to medications, and infections.

What Is Parkinson's Disease?

- ☐ Parkinson's disease (PD) occurs when brain cells that make dopamine, a chemical that coordinates movement, stop working or die.
 - ✓ It is called a **movement disorder**
 - ✓ But there are non-movement **symptoms**
 - ✓ PD is a lifelong and **progressive** disease
 - ✓ Experience with Parkinson's is unique to each person
- ☐ Symptoms and progression vary so you can not predict:
 - ✓ which symptoms you will get,
 - ✓ when you will get them
 - ✓ how severe they will be.

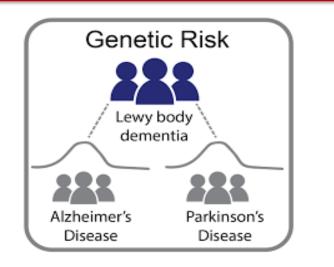
WE KNOW
WHAT MECHANISMS
PRODUCE THE SYMPTOMS.
WE DO NOT KNOW WHY.

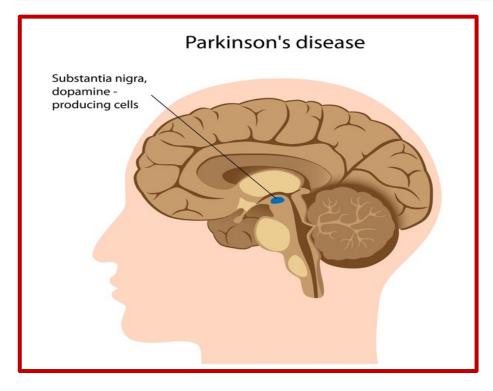
Parkinson's affects nearly 1 million people in the United States and more than 6 million people worldwide.

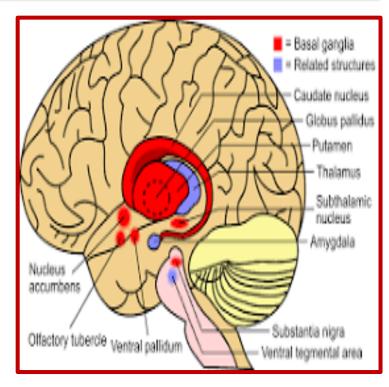
We Know What Happens But Not Why

- ☐ The most prominent symptoms of PD occur when nerve cells in the <u>basal ganglia</u> become impaired and/or die.
 - ✓ Normally, these nerve cells, or neurons, produce an important brain chemical known as *dopamine*.
 - ✓ Scientists still do not know what causes the neurons to die.
- People with PD also lose the nerve endings that produce <u>nore-pin-ephrine</u>, the main chemical messenger of the sympathetic nervous system, controlling the body's heart rate and blood pressure.
- The loss of <u>norepinephrine</u> might explain some of the non-movement features of Parkinson's, such as fatigue, irregular blood pressure, decreased movement of food through the digestive tract, and sudden drop in blood pressure when a person stands up.
- ☐ Many brain cells of people with Parkinson's disease contain <u>Lewy bodies</u>, unusual clumps of the protein alpha-synuclein.
- □ Scientists are trying to understand the functions of <u>alpha-synuclein</u> and its relationship to genetic variants that impact Parkinson's and <u>Lewy body dementia</u>.









- Some cases of PD appear to be hereditary, and a few cases can be traced to specific genetic variants.
 - ✓ Genetics cause about 10% to 15% of all Parkinson's.
 - ✓ In some families, changes (or mutations) in certain genes are inherited.
 - ✓ While genetics is thought to play a role in PD, in most cases the disease does not seem to run in families. Thus far no specific gene has been identified.
- ☐ Many researchers now believe that Parkinson's results from a combination of genetic and environmental factors, such as exposure to toxins.

What Are the Stages of Parkinson's Disease? Hoehn-Yahr staging system

- ☐ The H-Y staging system was created in 1967 by Drs. Hoehn and Yahr. .
- \Box The stages are:
- > Stage 1 the earliest stage. This includes mild tremors and mild difficulty walking. It affects only 1 side of the body. Loved ones may also notice less facial expression. These symptoms do not interfere much with daily life.
- > Stage 2 symptoms worsen. Tremors and difficulty moving now affect both sides of the body. Daily tasks are more difficult but still possible to complete independently.
- > Stage 3 –balance and coordination are now affected. Falls are a big concern. Help is needed for some tasks like dressing and feeding.
- > Stage 4 tasks become very challenging. Walking aids might be necessary. It may be difficult to live alone because most tasks require help.
- > Stage 5 the most severe stage. It may be difficult to stand and walk even with help. People most likely depend on a wheelchair or may be bedbound. New symptoms may develop, such as hallucinations or delusions.

MOTOR AND NON-MOTOR SYMPTOMS OF PARKINSON'S

MOTOR

☐ Tremors			
☐ Rigidity			
☐ Bradykinesia Bradykinesia means slowness of progressive hesitations/halts) as			
☐ Postural Instability			
☐ Vocal Symptoms LOUD	Since there isn't a specific test to diagnos Parkinson's, doctors diagnose it based		
☐ Writing Changes	on:		
☐ Walking or Gait Difficulties	1. Medical history,		
<u>NON-MOTOR</u>	 Review of signs and symptoms, Neurological and Physical exam. 		
☐ Depression and Anxiety			
☐ Disturbances in the Sense of Smell			
☐ Fatigue	At least some of these symptoms can		
☐ Gastrointestinal Issues. {IBS}	be assigned to the aging process.		
☐ Lightheadedness	It is difficult to tease out what is due		
☐ REM Sleep Disorders	to being 85+ and what is		
	Parkinson's.		

There are four primary motor symptoms of Parkinson's: ✓ tremor √ rigidity √ bradykinesia (slow movement) √ instability (balance problems) Observing two or more of these symptoms is the main way that physicians diagnose Parkinson's. Not all these symptoms must be present for a diagnosis of Parkinson's disease to be considered because: Not everyone with PD has a tremor. A tremor is not automatic proof of Parkinson's. Essential Tremor Disorder A nervous system disorder that causes rhythmic shaking that most often affects the hands, but it may affect the head, voice, arms, or legs. It's not related to Parkinson's disease. Shaking occurs with simple tasks as tying shoelaces, writing, or shaving. Symptoms may be aggravated by stress, fatigue, caffeine, and temperature extremes.

If needed, treatment may include medications, such as beta blockers.

PD Motor Symptoms * THOSE I'VE EXPERIENCED **Tremors** ✓ <u>Characteristically occurring at rest</u>, typically in one hand, foot, or leg. It began with my right THUMB * **Rigidity** ✓ Sometimes wrongly attributed to arthritis or orthopedic problems. **Bradykinesia {slowness of movement}** ✓ Typically demonstrated by > a reduced or mask-like expression of the face * > a decreased blink rate of the eyes > problems with fine motor coordination (difficulties buttoning a shirt) * trouble turning over in bed * > slow, small handwriting **Postural Instability** ✓ The inability to maintain a steady, upright posture or to prevent a fall. * Such balance problems in Parkinson's disease are associated with a tendency to list or fall backward (retropulsion).

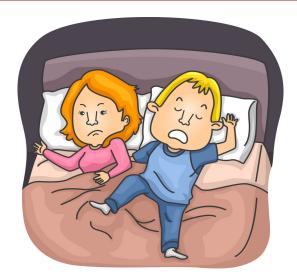
Non-Motor Symptoms * THOSE I'VE EXPERIENCED	
☐ Cognitive Changes	
✓ Problems with thinking, word finding, and judgment are common.	
✓ Difficulties in multi-tasking and organization, daily activities. Normal Agina?	
☐ Depression and Anxiety	
✓ Depression and anxiety are fairly common and can range in severity. *	
☐ Disturbances in sense of smell	
✓ Reduced sensitivity to odors (hyposmia) or a loss of smell (anosmia) are	
often early symptoms and <u>may be experienced months or years before typica</u>	! <u>l</u>
<u>motor symptoms emerge</u> . ☐ Fatigue	
✓ Fatigue is a complex symptom that is not fully understood, but is known to be associated with depression and sleep disorders.)
☐ Gastrointestinal Issues	٦
✓ Disturbances of the gastrointestinal system (IBS) are common. *	
A recent meta-analysis indicated that there is a significant association between IB	S

A recent meta-analysis indicated that there is a significant association between IBS and PD, and subjects with IBS have a higher risk of developing PD compared to those without IBS.

☐ Lightheadedness

- ✓ An estimated 30-60% of patients with Parkinson disease have orthostatic hypotension (OH), which can occur with or without symptoms.
- ✓ Classic symptoms of OH include dizziness, lightheadedness, and syncope. *
- ☐ REM Sleep Disorder
- **✓** Normally when dreaming the brain prevents muscles from moving.
- ✓ In some, these brain signals don't work properly, and a person moves while dreaming. * This is REM sleep behavior disorder (RBD).
- ✓ People with RBD often have very active dreams in which they're playing sports, running, or even being chased or attacked. *







AGING AND PD

- ✓ One does not need to be elderly for PD to occur.
- ✓ On the flip side, aging is not PD.
- ✓ Even in individuals aged 80 years and older, the prevalence of PD is in the range of 1% to 2% of the population.
- ✓ This shared biology and directionality of changes suggest that aging actively creates a vulnerable pre-parkinsonian state.
- ✓ This has important implications for aging as a critical variable in PD modeling and the vetting of potential therapeutic interventions.

The Tip of an Octogenarian's Tongue

By Barry Centíní

Having long passed the prime of my life,
I've developed a kind of linguistic strife.
Words that used to venture out to my tongue's tip,
now find refuge somewhere under my lower lip.

Words that popped out of my mouth without hesitation, just seem to sit there, not knowing their destination. "The word is right there; it's just at the tip of my tongue" is a phrase I readily use until my memory loss is undone.

The word is surreptitiously hiding just under my lip, and will slowly migrate outward at an octogenarian's clip. I can picture the object I'm trying desperately to name, but as is my new cognition, I choose the wrong memory lane.

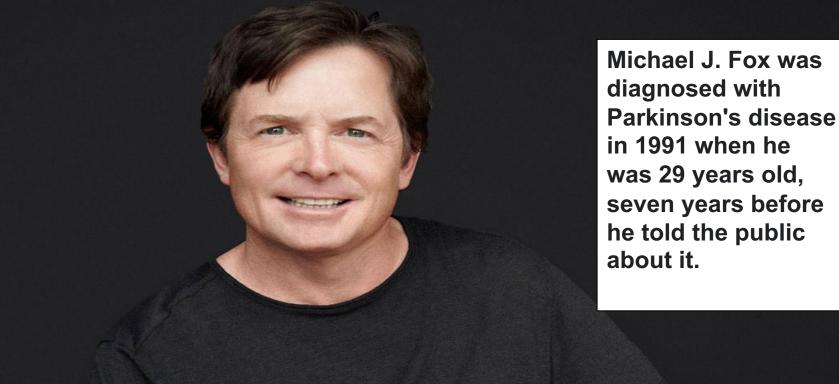
I look back with envy at my youthful, speedy, linguistic recall, when the proper word stood in an orderly line, awaiting its call. And when called, left the tip of my tongue with nary a delay, to continue the conversation with many new things to say.

It's painful to search for a word that you've said a thousand times; seeing it, practically feeling it, and knowing at least twelve rhymes. But eventually, and unexpectedly, the word pops into your brain, with a sacred promise that you will never forget it again.

This aging thing is definitely a one-way street with no rest stop! But to continue on life's journey we cannot be communication flops. Fight for your thoughts, and drive them up the tongue to the very tip, then use them with whatever communication skill you can still grip.

Early Onset Parkinson's Disease

What is Early Onset Parkinson's disease? Also named YOPD! ✓ It occurs in individuals between 21-50 years old. ✓ Symptoms are mostly the same, but young people experience them differently. **Symptoms of young onset PD:** ✓ involuntary movement problems due to levodopa. ✓ problems such as memory loss, confusion, and balance difficulties tend to be less frequent in young people with the disease. Who gets early onset PD? ✓ About 10%-20% of those diagnosed with PD are < 50 \checkmark ~ 90,000 new cases of PD/year means 9,000 – 18,000 young. Is it genetic or hereditary? Many researchers think that PD may be caused by genetic factors combined with other external factors.



About Parkinson's



Parkinson's 101	Newly Diagnosed Resources	Parkinson's IQ + You Events
Causes	Parkinson's 360°	Ask the MD
Symptoms	Building a Care Team	Webinars
Medications & Treatments	Work & Benefits	Podcasts
Related Conditions	Relationships	Books & Resources
Young- Onset	Mental & Physical Health	Real Talk from Patients
	Recursos en Español	Parkinson's Buddy Network

The Parkinson's Journey

Education & Inspiration

ABOUT ME AND MY PARKINSON'S



1955; age 18

MY PD SYMPTOMS

- 1. Tremor in my right thumb.
- 2. Tremor when eating.
- 3. Tremor in both hands and when eating.
- 4. Reduced facial expression.
- 5. Problems with fine motor coordination (buttoning a shirt)
- 6. Some trouble turning over in bed.
- 7. Had several "stumbling" falls.
- 8. Dizziness, lightheadedness on getting up after rest.
- 9. REM sleep behavior disorder (being chased).

Present PD Medications

- ☐ <u>Levodopa/Carbidopa</u> is a combination medication is used to treat symptoms of PD or Parkinson-like symptoms (such as shakiness, stiffness, difficulty moving).
 - ✓ Levodopa changes into dopamine in the brain, helping control movement.
 - ✓ Carbidopa prevents the breakdown of levodopa in the bloodstream so more levodopa can enter the brain.

'Off' time is when levodopa is no longer working well and symptoms such as tremor, rigidity and slow movement re-emerge.

So timing your dosage around meals is very important. Timed-release capsules is an answer for some.

- Rasagiline is used alone or with other medications (such as levodopa/carbidopa) to treat symptoms of Parkinson's disease.
 - ✓ It works by increasing the levels of certain natural substances in the brain (such as dopamine, norepinephrine, serotonin).
 - ✓ It can help improve symptoms such as shakiness, stiffness, and difficulty moving.
- ☐ <u>Clonazepam</u> is considered to be a first-line treatment for rapid eye movement (REM) sleep-related behavior disorder (RBD) in PD.
 - ✓ Anxiety and sleep disturbances are prevalent in PD.

My Efforts to Slow Down Progression

Rock Steady Boxing ✓ 1 ½ Hours/Week ✓ Great benefit! ✓ 6 punches 1=jab 2=cross 3-4 left-right hook, 5-6 left-right uppercut Swimming ~30-40 min/day Punch big bag daily Lift weights ~3/4 times/week BIG daily (at least that's my goal) Active in Greenspring Parkinson's Support Group



AFFILIATES BOXERS TRAINING CAMP ABOUT DONATE



60,000

PEOPLE DIAGNOSED WITH PARKINSON'S DISEASE ANNUALLY 871

ROCK STEADY BOXING PROGRAMS AROUND THE WORLD 43,500

PARKINSON'S BOXERS TRAINING AT AFFILIATE PROGRAMS WORLDWIDE





Advanced			

Save

Email

> Disabil Rehabil. 2022 Oct;44(20):6034-6041. doi: 10.1080/09638288.2021.1963854. Epub 2021 Sep 9.

High satisfaction and improved quality of life with Rock Steady Boxing in Parkinson's disease: results of a large-scale survey

Short Summary of Advanced and Future Treatments for Parkinson's **□** Deep Brain Stimulation. An implantable device to help reduce symptoms by generating small electrical pulses throughout the body. ☐ Gene Therapy Gene therapy has the potential to cure Parkinson's, slow its progression, or reverse the brain damage it causes. ☐ Neuroprotective Therapies Researchers are also developing neuroprotective therapies that could help stop the progression of the disease and prevent symptoms from getting worse. Biomarkers Staging, while useful, only monitors the progression of motor symptoms related to Parkinson's disease. NO Stage 4 Parkinson's! ✓ Researchers are hoping to discover a biomarker (a cell or gene) that will lead to more effective treatments. ■ Neural Transplantation Repairing the brain cells lost from Parkinson's disease is a promising area of future treatment. This procedure replaces diseased and dying brain cells with new cells that can grow and multiply...... ✓ And many, many more!

https://llinova.org

PARKINSON'S RESOURCES

https://www.parkinson.org

https://www.apdaparkinson.org

https://www.michaeljfox.orghttps://www.michaeljfox.org

https://www.parkinsonseurope.org

https://www.parkinsonalliance.org

https://www.parkinson.org/understanding-parkinsons/caring-for-someone-with-parkinsons

https://parkinsonfoundation.org/virginia-support-groups

https://www.inova.org/our-services/inova-parkinsons-and-movement-disorders-center



