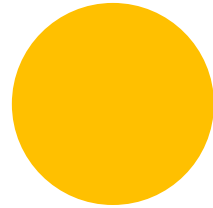


A Parkinson's Journey: Lessons Learned, Lessons to Share



Introductions

Steve DeWitte: Lessons – Learned, to Share

Susan Pelchat: Caregiver, Support Group Leader

Dr. deMarcaida: Research, Holistic View, PD Management

Dr. Tinaz: Exercise in PD

Q & A

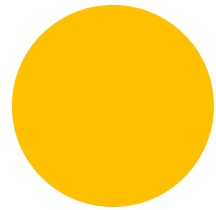
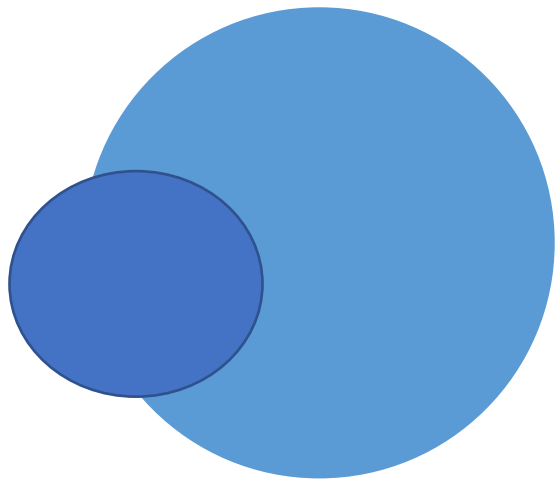
Agenda



A Parkinson's Journey: Lessons Learned, Lessons to Share

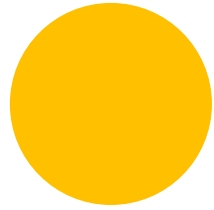
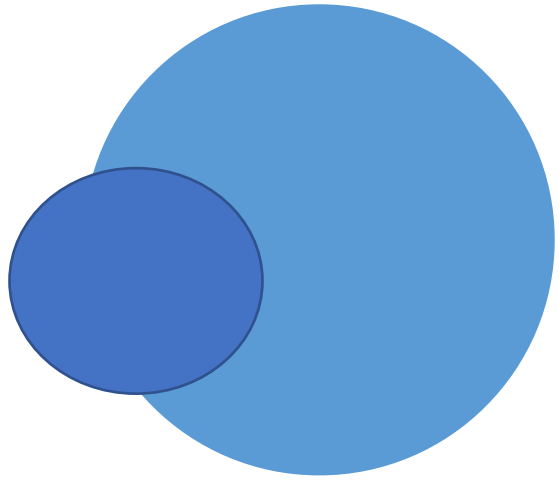
Presented by:

- A Person With Parkinson's (PwP) – Steve DeWitte
- Susan Pelchat, Support Group Leader & Caregiver to a PwP
- Dr. Joy Antonelle deMarcaida, Medical Director, Hartford Healthcare Chase Family Movement Disorders Center



Dr. Sule Tinaz-YSM
TAPSG
Brandywine Residents

Special Guests



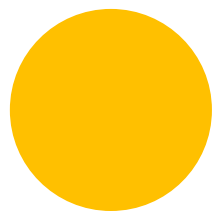
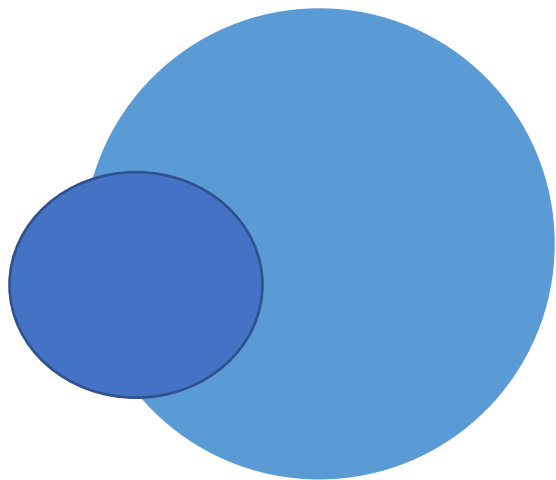
Hartford HealthCare 

Yale SCHOOL OF MEDICINE



With Special Thanks

Collaboration. Patient Voice. Transparency. Urgency



1. Be Your Own Best **Advocate**
2. Live Life With a **Purpose**
3. **Thank** a Doctor
4. **Participate** – events, support groups, research
5. **Volunteer** to help – someone, somewhere
6. Don't live life with Self Pity

Steve's Challenge to all
of us:

PATIENT PROFILE: Steve DeWitte

Diagnosed: March 2005

DOB: May 14, 1956 (68 yrs. Old)

Age at Diagnosis: 48 yrs. Old

Status: Married, one child

Residence: Here!
Brandywine Senior Living Community

Time with Disease: 20 years

Employment: Early retirement (Disability)

CONFESSIONS

Thoughts. From a “PwP”:

Although there are some similarities, each person has their **own Disease Profile**.

Symptoms and disease progression will differ from patient to patient, as will the treatment plan.

Sensitivity Welcomed ~ Leave “Pity” at the Door.

IN THE BEGINNING

- **SIGNS OF PARKINSON'S**
 - Loss of smell
 - Arm limp at side
 - Slight twitch of fingers
 - Face is without expression (Masking)
 - Constipation
 - Softening of Voice
 - Handwriting Deterioration
- High degree of misdiagnosis
 - Steve - misdiagnosed in November 2003 from a different Neurologist (NOT Dr. DeMarcaida!)
- Diagnosed March 2005 ~ Movement Disorder Specialist

Diagnosing Parkinson's Disease

Clinically diagnosed

UPDRS – BELIEVE IT OR NOT?!

U - Unified

P – Parkinson's

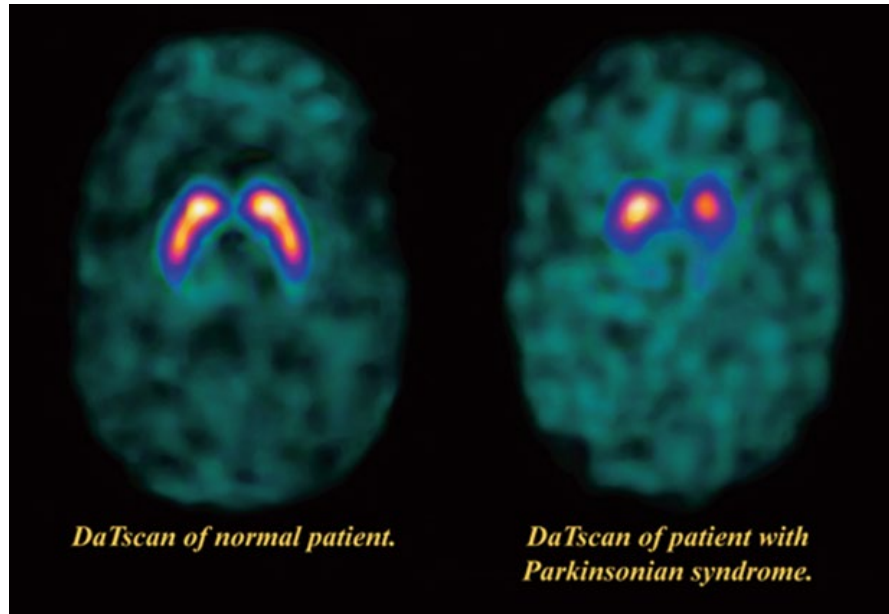
D – Disease

R – Rating

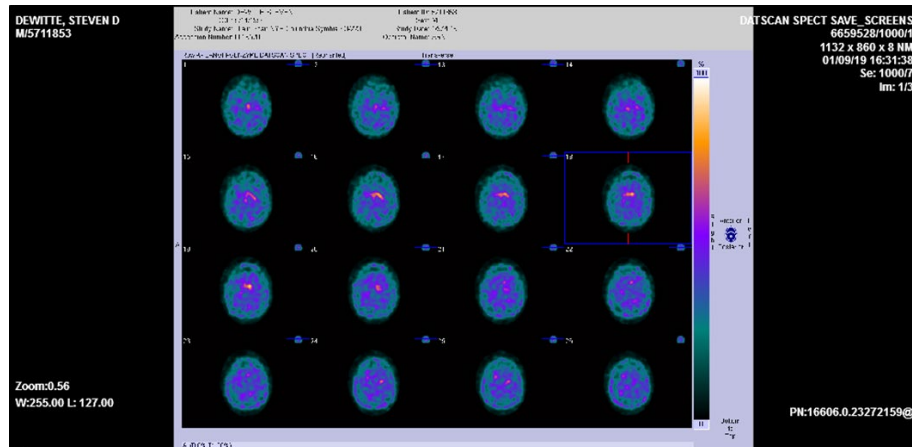
S – Scale



Healthy neuron/mutant neuron



Steve's Brain Scan



Imaging as a tool in diagnosis of PD



**From the
Front!**

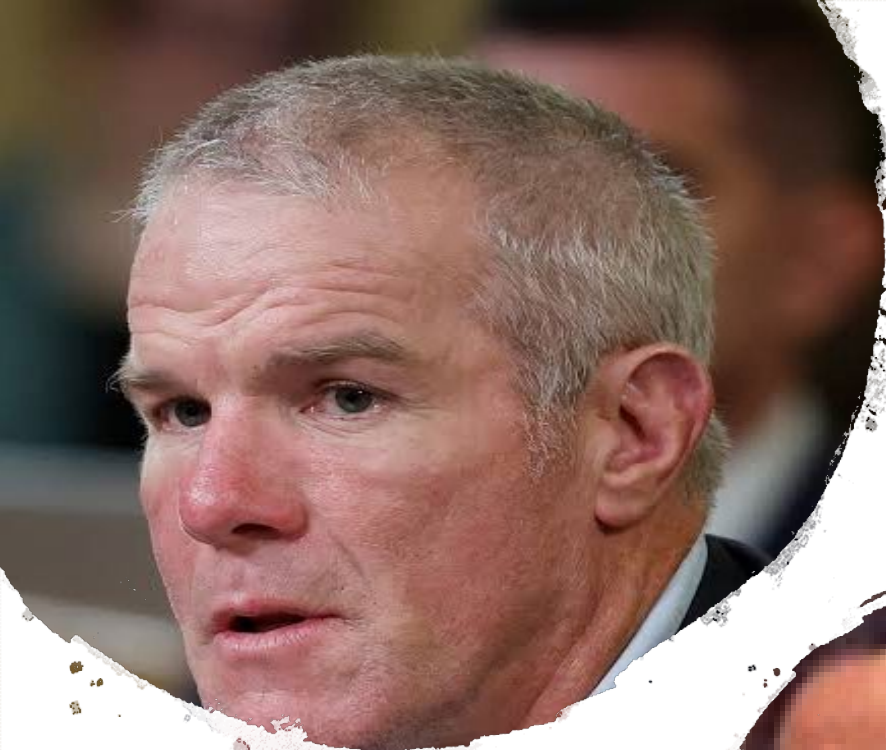
Musings:

“I think if I could treat my Patient’s symptoms of constipation and fatigue, they would be willing to live with the rest of disease”.

Dr. Bastian R. Bloem MD., PhD

Musings:

- ***Neurologist vs. MDS – know the difference***
- ***Care Teams – Social Work, Mental Health, Holistic, Nutrition, OT,PT, Support Groups, Alternative Medicine, Care Partners***
- ***Fall Risks & Balance***
- ***Geriatric vs Early Onset***



FACES OF PARKINSON'S



PARKINSON'S is **more** than
Michael J. Fox and
Muhammed Ali.....

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As the disease
Progresses....

Tremors

Rigidity

Impacts Gait (Shuffle)

Quality of Life

Strains on Family ~ A tribute to Care Partners

- Role Shifts
- Not able to do as much as I used to

Strains on Employment

- Not able to do as much as I used to
- Leaving the workforce ~ Navigating Disability

Managing the Disease

- Pill Regimen
- Exercise
- Clinic Visits – Treatments and Trials



Susan Pelchat



Support Group Leader, TAPSG
Wife
Caregiver
Teacher of the Year

- Personal Story
- Gadgets
- Life Changes
- Traveling
- Bucket List



Susan Pelchat





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Joy Antonelle de Marcaida, MD



Medical Director, Hartford
Healthcare Chase Family
Movement Disorders Center

- UPD/PRS
- Stages of Parkinson's
- Advice
- Q & A (at end)

Hartford 
HealthCare

Sule Tinaz, MD, PhD

Yale SCHOOL OF MEDICINE

Associate Professor of
Neurology





Sophie Holmes, PhD

Dr. Sophie Holmes is an assistant professor of psychiatry at Yale University. Her research focuses on the use of brain imaging to unravel the neural basis of psychiatric symptoms across psychiatric and neurological disorders. Building on her psychology background, Dr. Holmes realized the potential of imaging for understanding human behavior and mental illness and trained in applied neuroimaging, receiving her doctorate in neuropsychiatry from the University of Manchester (UK).



bit.ly/PDMJFF



bit.ly/DPIFR2025



bit.ly/PDFFOUND



bit.ly/PDAPDA1



HUBERMAN LAB

bit.ly/HUBERMAN



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RESOURCES

All links are UPPER CASE
Or Scan QR Codes



bit.ly/PDNCOA1



Parkinson Foundation in collaboration with the American College of Sports Medicine has established exercise criteria for PWP. Please see the links here:

<https://www.parkinson.org/library/fact-sheets/exercise-recommendations>

https://www.parkinson.org/sites/default/files/documents/exercise_guidelines_2022.pdf

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A faint, light gray background graphic of a stylized human figure. The figure has a circular head and a larger circular torso. The lines are thin and slightly irregular, giving it a hand-drawn or artistic feel. The figure is positioned on the left side of the page, with its arms and legs extending outwards.

Thank You!

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