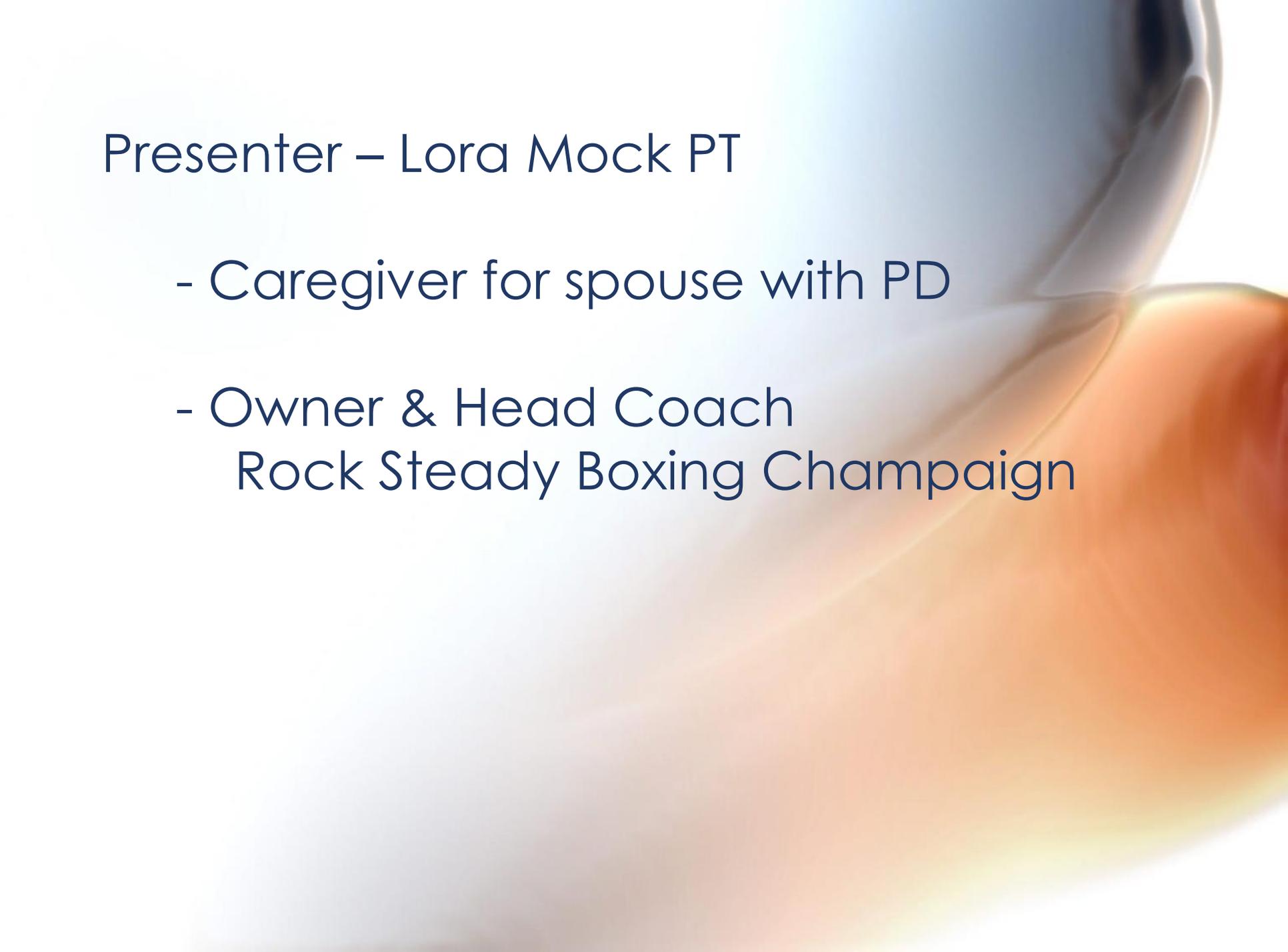


Parkinson's 101
and
Rock Steady Boxing as an
Effective Intervention



Presenter – Lora Mock PT

- Caregiver for spouse with PD
- Owner & Head Coach
Rock Steady Boxing Champaign

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**. Because PD can cause tremor, slowness, stiffness, and walking and balance problems, it is called a "movement disorder." But constipation, depression, memory problems and other non-movement symptoms also can be part of Parkinson's. PD is a lifelong and progressive disease, which means that symptoms slowly worsen over time.

What is Parkinson's Disease?

- Parkinson's affects **nearly 1 million people in the United States** and **more than 6 million people worldwide**.
- The experience of living with Parkinson's over the course of a lifetime is **unique to each person**. As symptoms and progression vary from person to person, neither you nor your doctor can predict which symptoms you will get, when you will get them or how severe they will be. Even though broad paths of similarity are observed among individuals with PD as the disease progresses, there is no guarantee you will experience what you see in others.

Cardinal Symptoms

2 of these 4 must be present over time for the neurologist to make a Parkinson's diagnosis

- Tremor - shakiness
- Bradykinesia – slowness of movement
- Rigidity – stiffness
- Postural instability – balance problems/falls

Dr. James Parkinson from England wrote in 1817,



Dr. James Parkinson
1755 – 1824

AN
ESSAY
ON THE
SHAKING PALSY.
=====
CHAPTER I.
DEFINITION—HISTORY—ILLUSTRATIVE CASES.
=====

SHAKING PALSY. (*Paralysis Agitans.*)

Involuntary tremulous motion, with lessened muscular power, in parts not in action and even when supported; with a propensity to bend the trunk forward, and to pass from a walking to a running pace; the senses and intellects being uninjured.

Conditions related to PD

- **Dyskinesia** is uncontrolled, involuntary movement that can look like fidgeting or wriggling. In Parkinson's, dyskinesia can happen with *long-term levodopa use and longer time with disease*. Many new therapies are working to prevent or treat this complication.
- **Dystonia** is painful muscle contractions that lead to *abnormal postures*. A symptom of Parkinson's and a movement disorder, dystonia affects about 500,000 people in the United States and Canada.

Atypical Parkinsonisms

- **Lewy Body Dementia**

People with Lewy body dementia (LBD) have the motor symptoms of Parkinson's but develop dementia (significant memory and/or thinking changes). Since Parkinson's and LBD share underlying biological changes, research into one may help treat the other.

- **Multiple System Atrophy**

This brain disease causes slowness, stiffness and walking problems, but people with multiple system atrophy also have more problems with the body's automatic functions (blood pressure, digestion). They also can have other symptoms, such as difficulty controlling emotions.

Atypical Parkinsonisms, (2)

- **Corticobasal Degeneration**

This brain disease causes movement, memory or thinking, and behavioral problems. Corticobasal degeneration (CBD) involves a build-up of a protein called tau. Scientists are working to measure and target tau with new treatments to stop CBD and other tau diseases.

- **Progressive Supranuclear Palsy**

Progressive supranuclear palsy (PSP) is another disease linked to a build-up of the tau protein. It causes movement symptoms, eye movement problems, and memory and thinking (cognitive) changes. Research into tau could help diagnose and treat PSP.

I think I might have Parkinson's disease and I'm not sure what to do

This screening questionnaire was developed by Dr. Joseph Jankovic, a member of the Scientific Advisory Board for the Michael J. Fox Foundation for Parkinson's Research, to help determine Parkinsonism and PD. If you answer yes to several of the questions below, you should discuss with your doctor or visit a movement disorders specialist.

I think I might have Parkinson's disease and I'm not sure what to do

This screening questionnaire was developed by Dr. Joseph Jankovic, a member of the Scientific Advisory Board for the Michael J. Fox Foundation for Parkinson's Research, to help determine Parkinsonism and PD. If you answer yes to several of the questions below, you should discuss with your doctor or visit a movement disorders specialist.

1. Have you been getting slower in your usual daily activities?

2. Is your handwriting smaller?

3. Is your speech slurred or softer?

4. Do you have trouble arising from a chair?

5. Do your lips, hand, arms and/or legs shake?

6. Have you noticed more stiffness?

7. Do you have trouble buttoning buttons or dressing?

8. Do you shuffle your feet and/or take smaller steps when you walk?

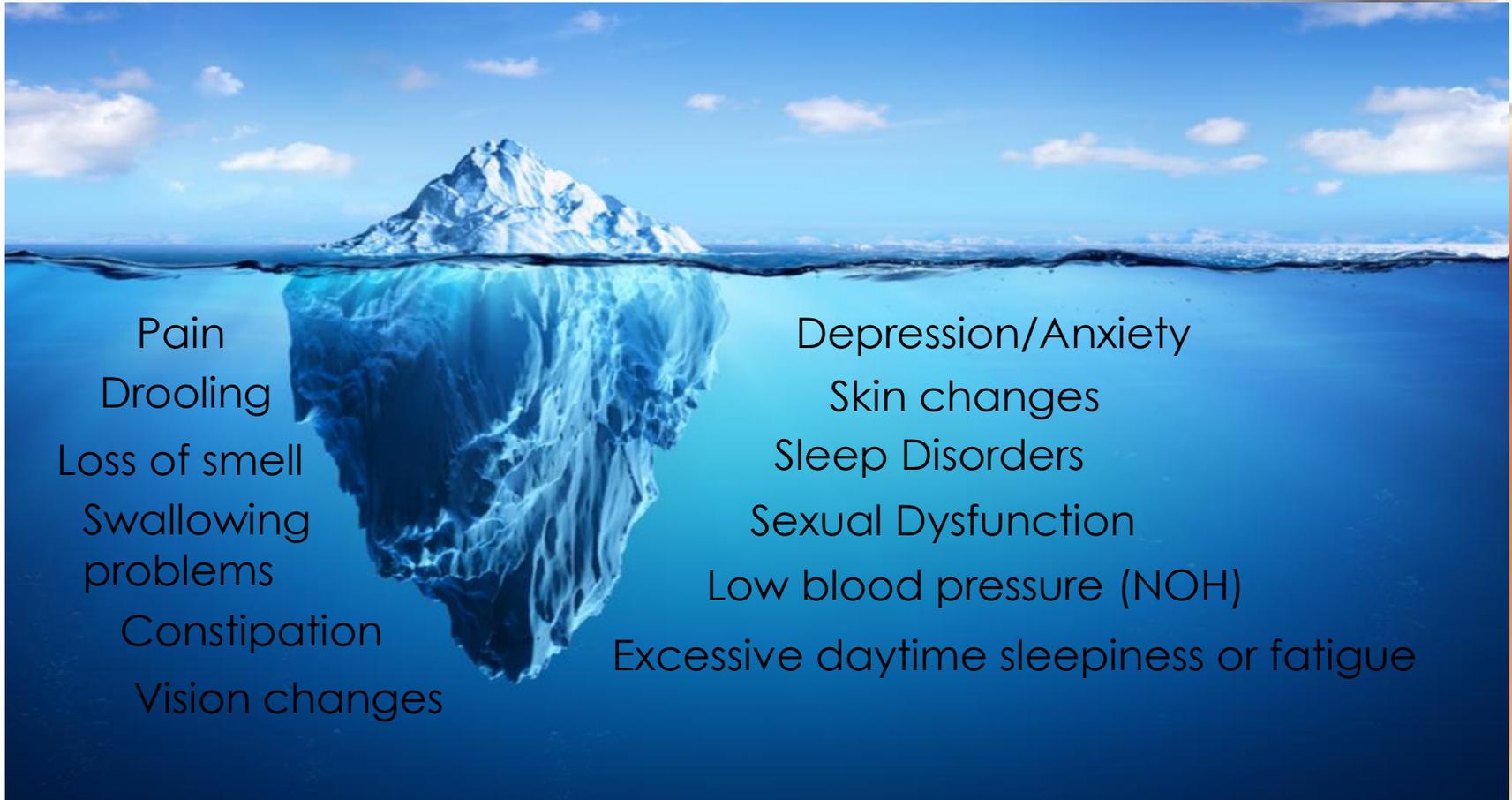
9. Do your feet seem to get stuck to the floor when walking or turning?

10. Have you or others noted that you don't swing one arm when walking?

11. Do you have more trouble with your balance?

12. Have you or others noted that you stoop or have abnormal posture?

Non-Motor Parkinson's Symptoms



Pain
Drooling
Loss of smell
Swallowing
problems
Constipation
Vision changes

Depression/Anxiety
Skin changes
Sleep Disorders
Sexual Dysfunction
Low blood pressure (NOH)
Excessive daytime sleepiness or fatigue

Young Onset Parkinsons Disease (YOPD) Or Early Onset PD

- Diagnosis before age 50
- 10-20% of those diagnosed with PD
- People with young-onset Parkinson's disease (YOPD) may have a **longer journey to diagnosis**
- When younger people and their clinicians are not expecting Parkinson's disease (PD), the diagnosis may be missed or delayed. It's not uncommon for arm or shoulder stiffness to be attributed to arthritis or sports injuries before Parkinson's is eventually diagnosed.

Young Onset Parkinsons Disease

- People with YOPD are more likely to experience [dystonia](#) — prolonged muscle contractions that lead to abnormal postures, such as twisting of the foot.
- Younger people are more likely to develop [dyskinesia](#) — involuntary, uncontrolled movements, often writhing or wriggling — as a complication of long-term [levodopa](#) use combined with a long course of Parkinson's disease.

Causes

- In everyone with Parkinson's, both genetic changes and environmental factors likely contribute, to different degrees, to cause the disease. In younger people, especially those who have multiple family members with Parkinson's, **genetics may play a larger role**. Certain genetic mutations (in the *PRKN* gene, for example) are associated with an increased risk of young-onset PD.

Young-onset Considerations

- Support group for YOPD

- Employment considerations

Having a backup plan, including schedule changes, early retirement or even a different career, may be worthwhile.

- Finances

Map out future financial goals and reevaluate life insurance coverage. Explore disability and long-term care insurance options

- Family Planning

Although the data on pregnancy and PD is limited, plenty of women with Parkinson's disease have successfully carried healthy babies to term.

Taking birth control pills does not mean you cannot take Parkinson's drugs, but doses may need to be adjusted.

Care Givers and Families

When one person in a couple or family is affected by Parkinson's disease, the other family members live with it as well. To keep your care partnering relationship healthy and balanced, it's important that the care partner finds time to **take a break** from caregiver duties, has some **outside interests**, and **has others** they can turn to for support and resource information.

Care Givers and Families

- **We do great work** without receiving the reimbursement, support, help, or assistance we need.
- **We go it alone.**
49% of survey respondents in our [2017 Annual Family Caregiver Survey](#) say they receive no help from family members. 74% say they do not have a back-up or a trained back-up to provide care in their absence if they become ill, have an emergency or want to take a vacation.
- **We all feel it.**
In our [simple stress survey](#), 1,044 family caregivers rated their stress level on a scale of 1 to 5 with 5 being the most stressed. The current number is 4.14. A little over 80% of survey respondents rated their stress level as a 4 or 5.
- **It's constant.**
46% of survey respondents in our 2017 Annual Family Caregiver Survey say they have between two and eight hours of time for themselves each week. That's less than one hour each day of time we can call our own.

Care Givers and Families

- **We can't find what we need** in our communities to help us cope.
- **We put our wellness on hold.**

60% of survey respondents said they do not adequately take care of their physical, emotional, dental and medical needs.

- **It costs businesses.**

According to AARP, hidden costs to employers include the estimated tab of \$6.6 billion to replace employees who quit or retire early. In addition, employers may be losing an estimated \$6.3 billion because of workday interruptions as employees *arrive late, leave early and take time off during the day* because of caregiving responsibilities.

14 Warning Signs of Caregiver Burnout

- Lack of energy
- Overwhelming fatigue
- Sleep problems (too much or too little)
- Changes in eating habits; weight loss or gain
- A feeling of hopelessness
- Withdrawing from, or losing interest in, activities you once enjoyed

14 Warning Signs of Caregiver Burnout

(Page 2)

- Neglecting your own physical and emotional needs
- Feeling like caregiving is controlling your life
- Becoming unusually impatient, irritable or argumentative—with the person you're caring for and/or with others
- Anxiety about the future
- Depression or mood swings
- Difficulty coping with everyday things
- Headaches, stomachaches, and other physical problems
- Lowered resistance to illness

7 Tips to Avoid Caregiver Burnout

- Let family lend a hand. A family meeting can help sort out everyone's schedules so you get regular breaks.
- Involve friends. Create a list of things that need to be done. When they ask, point to the list.
- Take regular breaks. Even if only 15 or 20 minutes a day, make sure you do something for you.
- Exercise. Whether it is a 20-minute walk outside or taking a yoga class, exercise is a great way to decrease stress and increase energy.
- Eat healthy. Your health and nutrition are just as important as your loved one's, so take the time to eat well.
- Attend a [support group for caregivers](#). Your local hospice, hospital or senior service might be offering one.
- Seek professional help. Many caregivers feel lonely, anxious, guilty, angry, scared, confused or tired. If these feelings are overwhelming, call your doctor, hospice or another community resource for help.

Caregiving Resources

Join APDA's new online community support forum with [Smart Patients](#).

Visit the [Ask the Doctor](#) section of the APDA website.

Download our publication called [Becoming a Care Partner](#) to learn about ways you can handle some of the challenges of being a care partner.

In-home services in their community. For more information please visit [Get Palliative Care](#).

<https://www.apdaparkinson.org/resources-support/for-caregivers/>

Caregiving Resources

- <https://www.caregiving.com/>
Caring for You as You Care for Family
- <https://www.aarp.org/caregiving/?cmp=KNC-BRD-MCPP-REALPOSS-TODAY-BING-SEARCH-CAREGIVING&gclid=CMHn-ub3w-MCFYSIxQldsWEGJQ>
AARP – Family Caregiving
- <https://www.caregiving.org/resources/>
National Alliance for Caregiving
- <https://www2.illinois.gov/aging/CommunityServices/caregiver/Pages/crc.aspx>
Illinois Department of Aging



- Q and A



- Audience experience

Rock Steady Boxing

- **History**

- * Scott Newman – Attorney. YOPD. Police officer friend introduced him to boxing. Saw lessening of symptoms.
- * Hired retired professional woman boxer

- **Research**

- * Cleveland Clinic Study
- * Bicycle exercise 3x a wk for 8 wks
- * Some at voluntary level
- * Others at forced-rate exercise using a modified bike to induce forced activity.
- * “The results showed that FORCED INTENSE EXERCISE is a more effective therapy to reduce symptoms of Parkinson’s disease”

From Rock Steady Boxing Volunteer Orientation

Rock Steady Boxing

* University of Indianapolis - 2011

Stephanie A. Combs, M. Dyer Diehl, William H. Staples, et al. Boxing Training for Patients With Parkinson Disease: A Case Series. *Journal of Physical Therapy*. 2011; 91:1, pg 1-12.

“This case series is the first report of the effects of boxing training in patients with PD.”

“Except for patient 6, all patients showed improvements in every outcome category, including balance, gait, disability, and quality of life...”

These positive changes may be indicative of the whole-body approach of the boxing training program, which incorporated dynamic balance activities...

 multidirectional reaching and stepping...

 agility drills...focused on the initiation of movement and fastpaced changes in direction...

patients with mild PD showed improvements earlier than patients with moderate to severe PD, particularly in the gait-related out-come measures.”

“However, patients with moderate to severe PD did eventually show improvements in most outcome measures, suggesting that they required a longer training duration to acquire the necessary training capacity.”

“Another key observation of this case series was that all patients continued to make improvements in balance, gait, and quality of life up to the 24- and 36-week tests despite the reduction in attendance after the initial 12 weeks.”

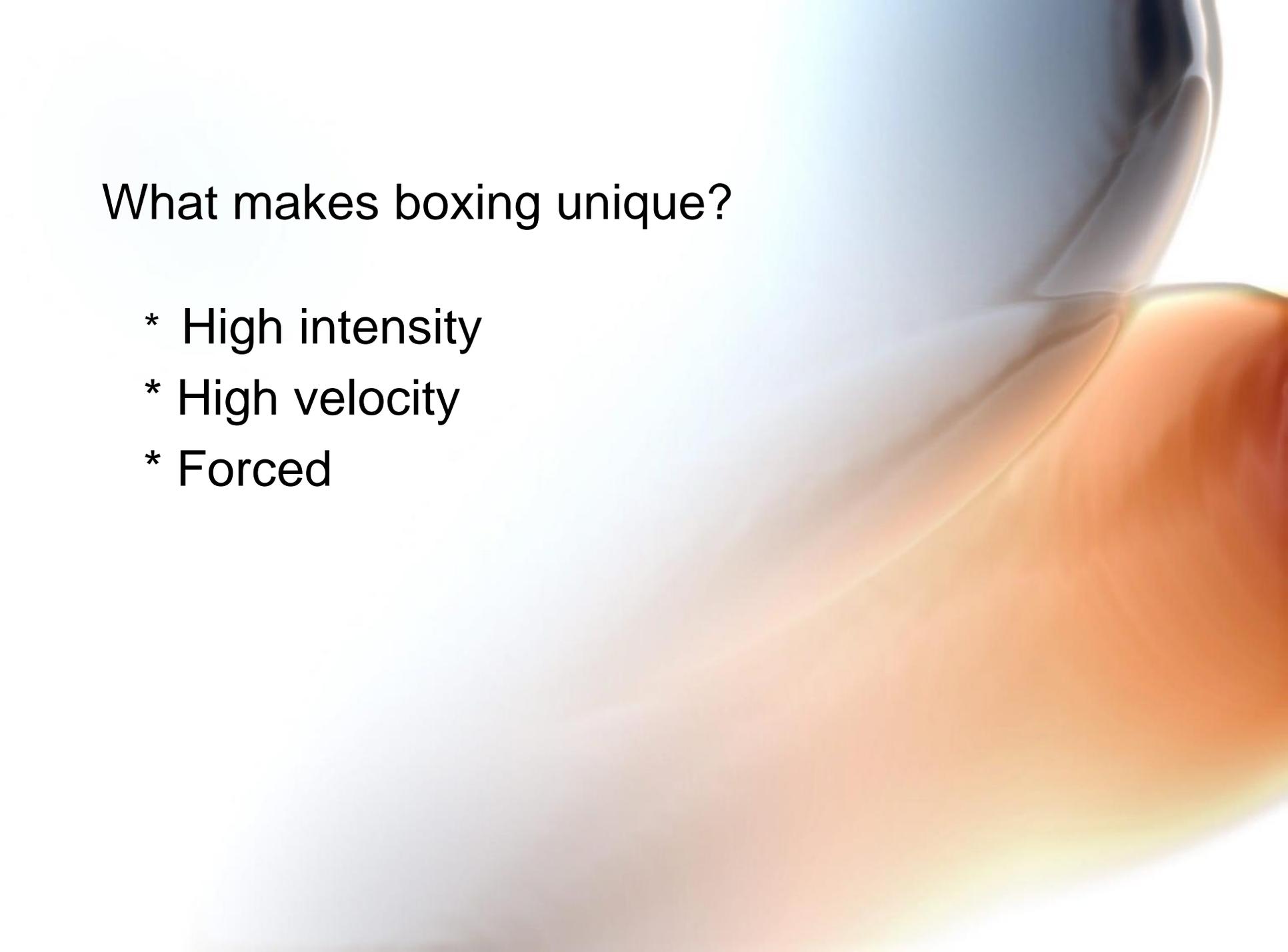
“We were able to demonstrate that group boxing training was feasible for patients in this case series regardless of the level of PD severity.”

Rock Steady Boxing

- Rocksteadyboxing.org
- Exercise is just as important as medicine.
- Starting early after the diagnosis is important, but it's never too late to start.
- Important to find an exercise regime that you enjoy and will continue for the long-term.

What makes boxing unique?

- * High intensity
- * High velocity
- * Forced



Boxing benefits vs Parkinson's

Motor Symptoms: Improve:

- Tremor
- Bradykinesia
- Rigidity
- Postural Instability
- Stooped Posture
- Freezing
- Shuffling gait

Secondary Symptoms:

- Cognitive Issues
- Depression
- Emotional Changes

Boxers Train to

- Hand-eye coordination
- Speed of movement
- Flexibility
- Optimal Balance
- Shuffling Gait
- Rapid Muscle Fire
- Agility

Boxers workout:

- Improve mental focus
- Reduce stress
- Improve mood

Functional Fitness

- Walk Better
- Fall Better
- Get up and down safely
 - Increase Rotation
 - Balance
 - Voice Activation
- Happiness & Fun

Additional References & Resources

- Michael J. Fox Foundation

<https://www.michaeljfox.org>

- American Parkinson Disease Association

<https://www.apdaparkinson.org/community/st-louis/>

<https://www.apdaparkinson.org/community/midwest/>

- Parkinson's Foundation

<https://www.parkinson.org/>

- Davis Phinney Foundation

<https://www.davisphinneyfoundation.org/>

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- Q and A