RVNAHEALTH™
For Lifelong Care & Wellness

Intro to PD

Hosted by

RVNAhealth Parkinson's Center

April 26, 2023

Gigi Weiss
Parkinson's Center Director

- **Physical Therapist**
- MSPT, LSVT BIG, CDP, CADDCT
- RVNAhealth Director of Rehabilitation Services
- Oversees clinical and business operations of home health therapy, outpatient Rehabilitation and Wellness, and Parkinson's Center
- Expert topics: Exercise prescription, Vestibular rehab, Fall Prevention, and Dementia Practitioner Trainer

RVNAhealth Continuum of Services

BEWELL
Services to Keep You Healthy

- Community Health & Wellness
- Individual Health & Wellness
- Chronic Care Management
- Public Health & Safety

COMFORTWELL
Hospice Care to Provide Comfort and Peace

- Palliative Care
- Hospice Care

GETWELL
Services to Recover Your Best Health

- In-Home Skilled Nursing
- In-Home & Outpatient Rehabilitation Therapy Services
- Parkinson's Center

STAYINGWELL
Services to Remain Safely in Your Home

- Personal Caregiver Services
- Care Planning & Management
- Private Duty Nursing
- Personal Medical Alert Service

Objectives

- Educate People with Parkinson's (PWP) about
  - Parkinson's Disease pathology and diagnosis
  - Symptoms and symptom management
  - Living their best life with Parkinson's
- Provide Resources
- Introduce the RVNAhealth Parkinson's Center provide further support and resources
- Establish baselines in PD symptoms

Physical Therapist's Role in PD

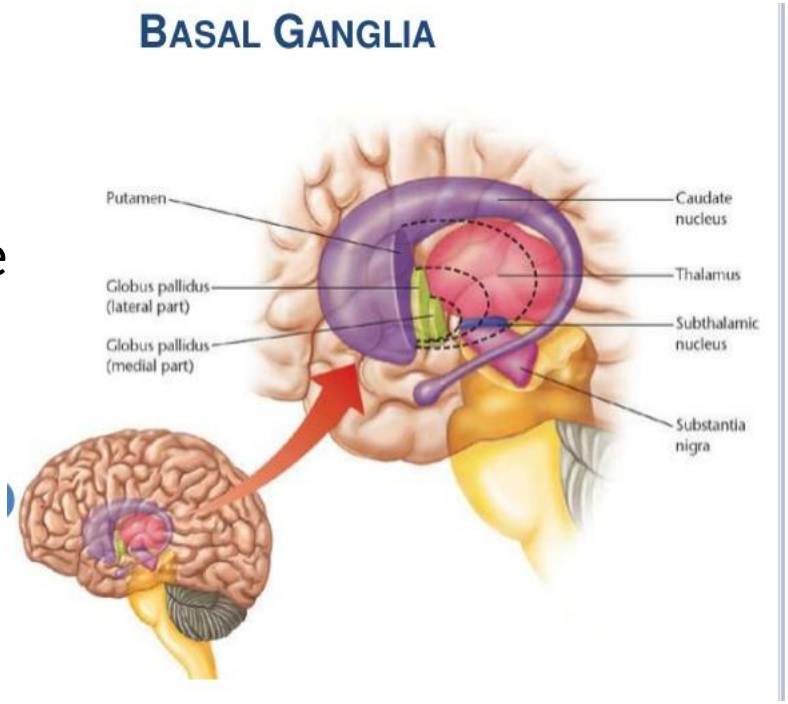
- Evaluation and Overall Assessment:
  - Body functions: Mobility, i.e., walking, balance, strength and flexibility
- Establish baselines
- Create a plan of care (POC) from findings
- Make recommendations to other needed services
- Establish Joint Goals:
- PT can increase mobility, strengthen muscles, improve coordination and balance, in the efforts to maintain level of function

Kate Campbell
Parkinson's Center Program Manager

- **Physical Therapist**
- DPT, SCS, Cert. MDT, CSCS, LSVT BIG, CDP
- RVNAhealth Rehabilitation & Wellness Center Outpatient Practice Manager
- Oversees treatment of patients at RRWC and at the Golf Performance Center
- Treating Parkinson's patients with LSVT BIG since 2016
- Expert Topics: Exercise prescription, Balance assessment, How to Fall, Fall Prevention

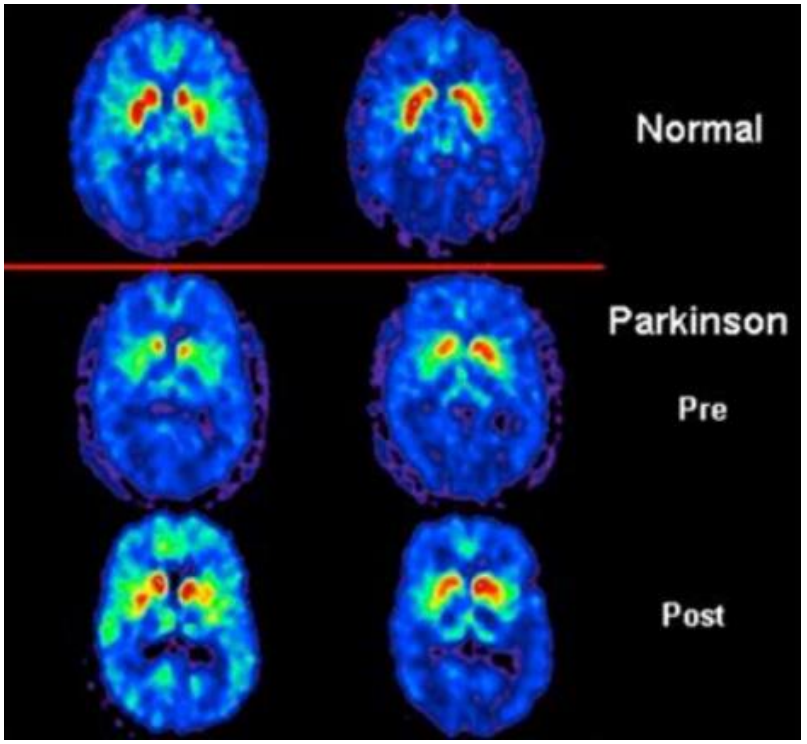
What is Parkinson's Disease?

- Neurodegenerative disorder
- Lack of dopamine in the brain
  - Produced Substantia Nigra
  - Coordinates movement
  - Released in response to pleasure
  - Regulates mood and emotions
- Basal Ganglia uses Dopamine
  - Control Movement
  - "Subconscious movement"
  - Central Gait Pattern



How is PD Diagnosed?

- Neurologist or Movement Disorder Specialist
- Diagnosis Process:
  - Medical history
  - Physical exam, Symptoms -> try meds
  - DaTscan vs PET scans
  - Eventually blood tests with biomarkers



Common Symptoms - Motor

- Lack of Dopamine in the Basal Ganglion:
  - GET READY signal too weak
  - GO signal too weak
  - NO GO signal too weak
- Bradykinesia – slowed movements
- Cogwheel Rigidity - stiffness
- Resting Tremor
- Festinating Gait – freezing
- Postural Instability

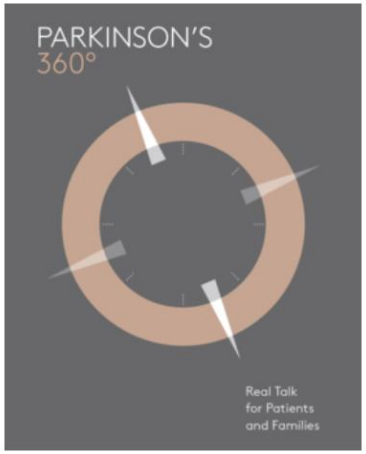
Common Symptoms – Non-Motor

- **Changes in higher cognitive functions**
- **Emotional Changes**
  - Anxiety
  - Apathy
- **Sensory changes**
  - Pain, **tingling, burning**
  - **Generalized decreased kinesthetic awareness/proprioception**
    - **Self-perception/monitoring**
- **Autonomic changes**
  - Hypotension, bowel/bladder, constipation, sexual, blurry vision, short of breath
- **Sleep Disorders**
- **Depression**
  - 25% major/17% minor
  - Precedes motor symptoms
  - May contribute to dementia
- **Dementia**
  - 30%
  - Occurs 6.6X as frequently than in elderly without PD

Motor and non-motor symptoms affect movement and motor learning in people with PD

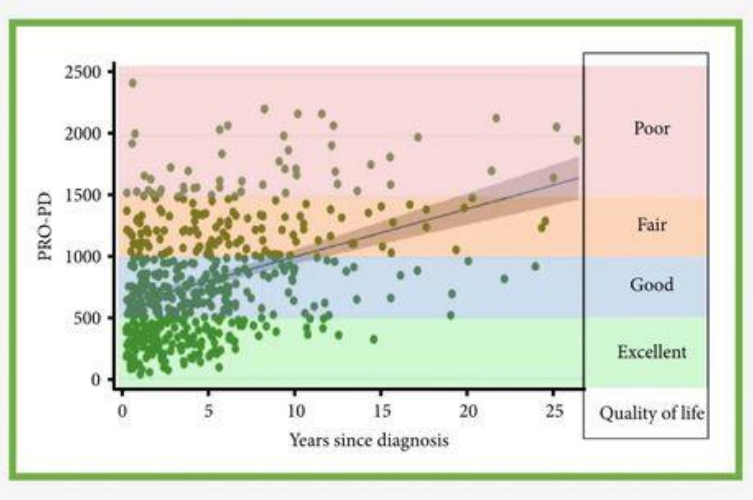
Resources

- RVNAhealth.org/ParkinsonsCenter
- Parkinson's Foundation: Parkinson.org
  - Free books
  - Hospital Kits
  - Education and resources
- MichaelJFox.org
  - Parkinson's 360° Guide for navigating Parkinson's
- Davis Phinney
  - davisphinneyfoundation.org/
  - https://davisphinneyfoundation.org/every-victory-counts-manual/



Resources

- Got a trainer? Ask them to get this free certification https://www.apdaparkinson.org/pd-fitness-training/
- To apply for a grant from the Parkinsons Wellness Fund: https://parkinsonswellnessfund.org/
- PD alliance: https://www.pmdalliance.org/
- Mediflix Parkinson's Programming: https://mediflix.com
- Fill out the Pro-PD - its a self rated scoring test https://educationismedicine.com/pro-pd



Mischley LK, Lau RC, Bennett RD. Role of Diet and Nutritional Supplements in Parkinson's Disease Progression. Oxid Med Cell Longev. 2017;2017:6405278. doi: 10.1155/2017/6405278. Epub 2017 Sep 10. PMID: 29081890; PMCID: PMC5610862.

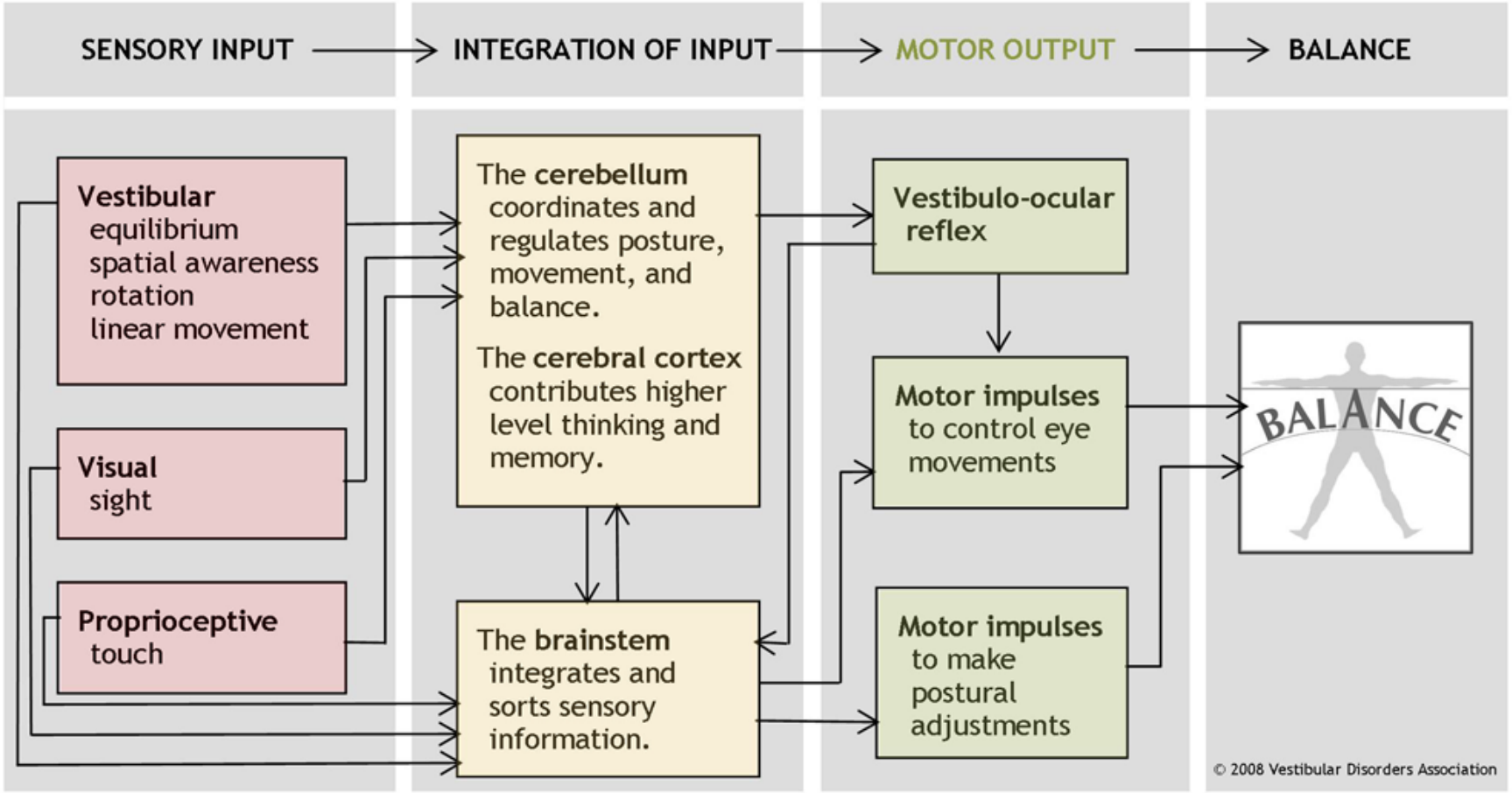
Join a Study

- www.michaeljfox.org/join-study
- https://www.parkinson.org/advancing-research/join-study
- https://medicine.yale.edu/ycci/clinicaltrials/find/

Balance

- The ability to maintain the body's center of mass over its base of support.
- Allows
  - See clearly while moving
  - Orient to gravity
  - Adjust posture to remain stable

Balance


SENSORY INPUT
INTEGRATION OF INPUT
MOTOR OUTPUT
BALANCE
Vestibular
equilibrium
spatial awareness
rotation
linear movement
Visual
sight
Proprioceptive
touch
The cerebellum coordinates and regulates posture, movement, and balance.
The cerebral cortex contributes higher level thinking and memory.
The brainstem integrates and sorts sensory information.
Vestibulo-ocular reflex
Motor impulses to control eye movements
Motor impulses to make postural adjustments
BALANCE
© 2008 Vestibular Disorders Association

Physical Therapist's Role in PD

- Assess balance
  - Tests for each system
- Prescribe exercises for home
- Prescribe exercises for in clinic
  - Successful exercises induce LOB

Summary – what you can do NOW

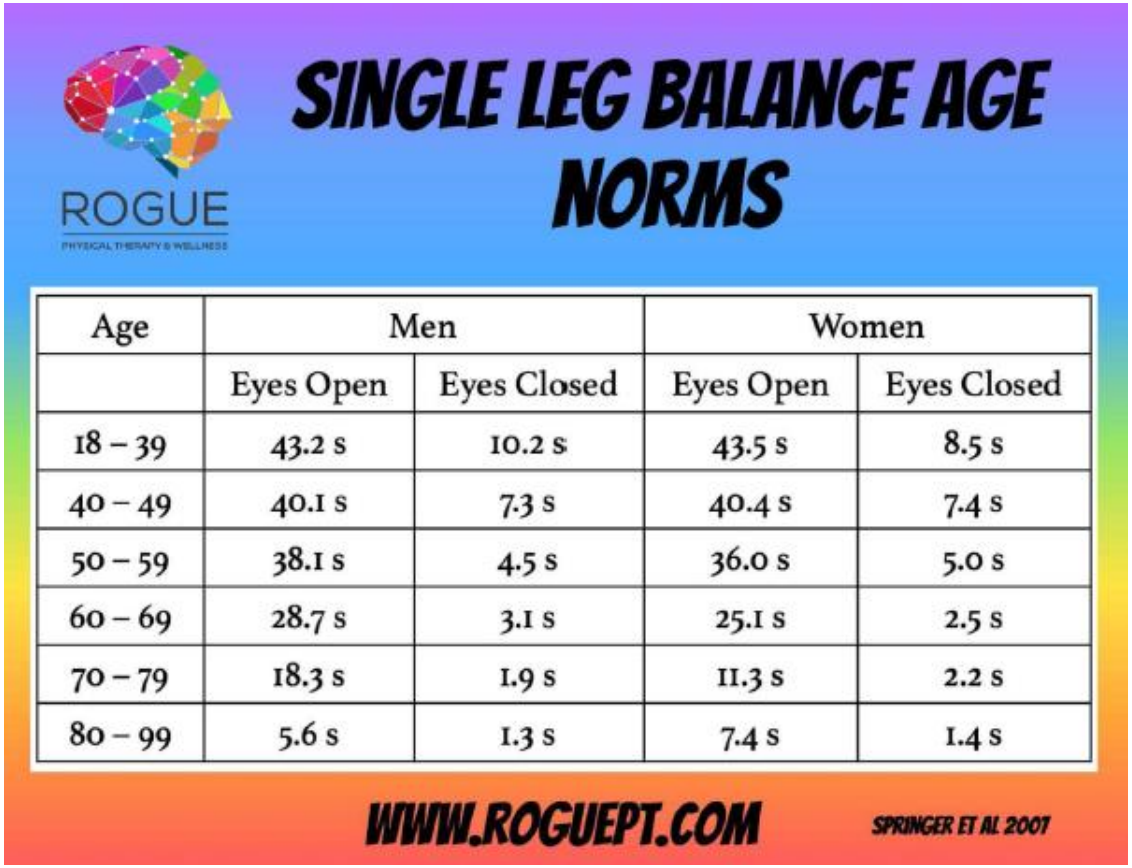
- Assess balance
  - Consult a physical therapist
  - Benefit: experience with Parkinson's, neurological conditions, geriatrics
- Start balance exercises
  - GOAL – challenging but successful
  - Single leg stance
  - Walk with head turns
  - Feet together eyes closed

Baseline Time

- Balance
  - Single leg stance
  - Turning 360°
- Strength
  - 30 Second Sit to Stand
- Walking
  - Gait Speed
- Self Efficacy
  - PDQ-8
- Self Assessment PD Disability Scale
- Pro-PD score https://educationismedicine.com/pro-pd
  - Take at home, email us your results please PCInfo@rvnahealth.org

Baseline Time

- Single leg balance
- 10 seconds 84% increased risk of death over next seven years



Age	Men		Women	
	Eyes Open	Eyes Closed	Eyes Open	Eyes Closed
18 – 39	43.2 s	10.2 s	43.5 s	8.5 s
40 – 49	40.1 s	7.3 s	40.4 s	7.4 s
50 – 59	38.1 s	4.5 s	36.0 s	5.0 s
60 – 69	28.7 s	3.1 s	25.1 s	2.5 s
70 – 79	18.3 s	1.9 s	11.3 s	2.2 s
80 – 99	5.6 s	1.3 s	7.4 s	1.4 s

Baseline Time

Turning 360°

Below Average

- > 5.74 seconds
- > 9 steps

Average

- 4.1 seconds to 5.6 seconds
- 5-8 steps

Above average

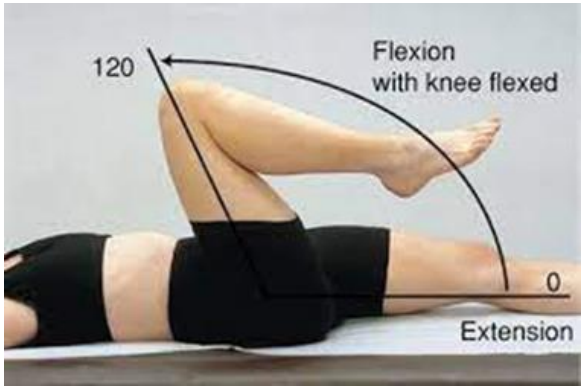
- <4 seconds and 4 steps or less

Andrea de Lange
Parkinson's Center Clinical Lead

- **Physical Therapist**
- CERT MDT, LSVT BIG, CDP
- Focus on evidenced based care to center
- PD Bootcamp facilitator and trainer
- Treats Parkinson's Center patients in outpatient clinic
  - Able to combine orthopedic expertise with Parkinson's education
- Leads exercise classes
- Expert Topics: Pelvic Health, Exercise Prescription, Fall Prevention and How to Fall, Care Partner Education, Research Trial Participation

Physical Therapist's Role in PD

Strength Assessment



Mobility and Flexibility Assessment

Posture Assessment

Physical Therapist's Role in PD

Walking Assessment

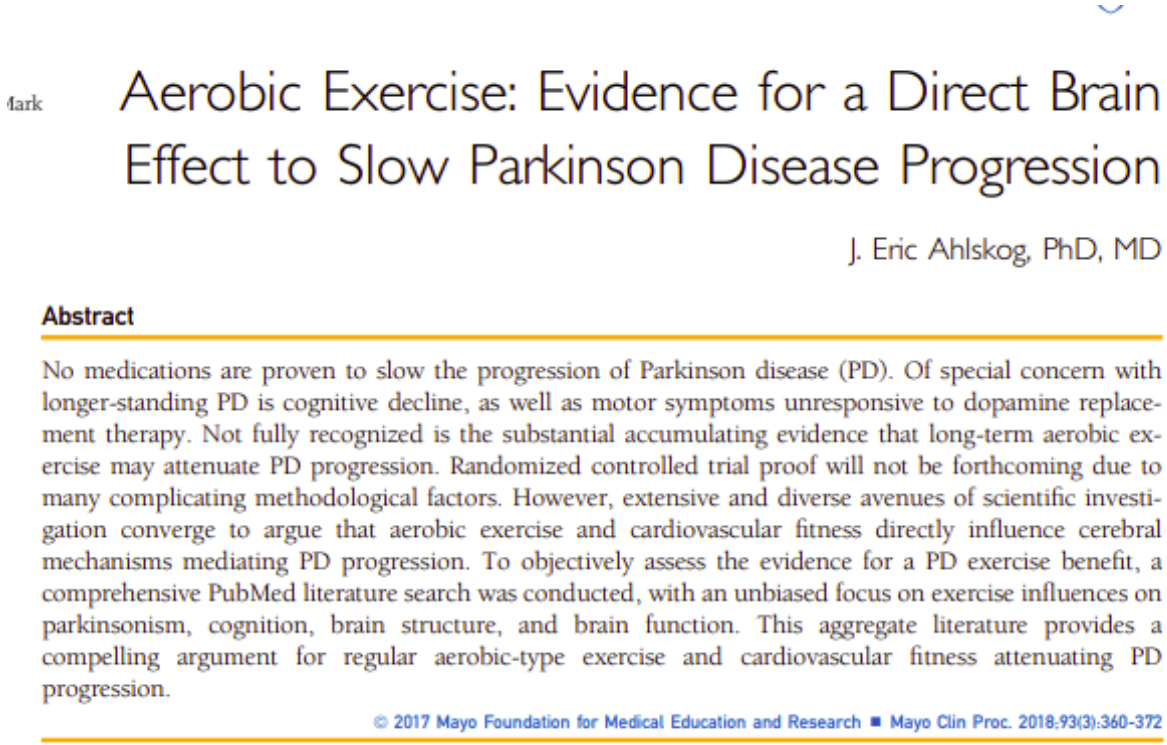
Balance Assessment

Cognitive Screen

Fall Risk Assessment

Paul SS, Canning CG, Sherrington C, Lord SR, Close JC, Fung VS. Three simple clinical tests to accurately predict falls in people with Parkinson's disease. Mov Disord. 2013 May;28(5):655-62. doi: 10.1002/mds.25404. Epub 2013 Feb 28. PMID: 23450694.

Why is Exercise Important?



Mark

Aerobic Exercise: Evidence for a Direct Brain Effect to Slow Parkinson Disease Progression

J. Eric Ahlskog, PhD, MD

Abstract

No medications are proven to slow the progression of Parkinson disease (PD). Of special concern with longer-standing PD is cognitive decline, as well as motor symptoms unresponsive to dopamine replacement therapy. Not fully recognized is the substantial accumulating evidence that long-term aerobic exercise may attenuate PD progression. Randomized controlled trial proof will not be forthcoming due to many complicating methodological factors. However, extensive and diverse avenues of scientific investigation converge to argue that aerobic exercise and cardiovascular fitness directly influence cerebral mechanisms mediating PD progression. To objectively assess the evidence for a PD exercise benefit, a comprehensive PubMed literature search was conducted, with an unbiased focus on exercise influences on parkinsonism, cognition, brain structure, and brain function. This aggregate literature provides a compelling argument for regular aerobic-type exercise and cardiovascular fitness attenuating PD progression.

 ■ Mayo Clin Proc. 2018;93(3):360-372

Aerobic Exercise: Evidence for a Direct Brain Effect to Slow Parkinson Disease Progression

Ahlskog, J. Eric

Mayo Clinic Proceedings, Volume 93, Issue 3, 360 - 372

Why is Exercise Important?

- A myriad of animal studies document a direct, favorable effect of aerobic-type exercise on the brain; this includes liberation of neurotrophic hormones and enhancement of a variety of neuroplasticity mechanisms. Exercise tends to protect animals from neurotoxins that induce parkinsonism.

Aerobic Exercise: Evidence for a Direct Brain Effect to Slow Parkinson Disease Progression
Ahlskog, J. Eric
Mayo Clinic Proceedings, Volume 93, Issue 3, 360 - 372

Why is Exercise Important?

- Long-term exercise and fitness in healthy humans is associated with greater volumes of cerebral cortex and hippocampus and less age-related white matter pathology.

Aerobic Exercise: Evidence for a Direct Brain Effect to Slow Parkinson Disease Progression
Ahlskog, J. Eric
Mayo Clinic Proceedings, Volume 93, Issue 3, 360 - 372

Why is Exercise Important?

- **Midlife exercise is associated with a significantly reduced later risk of Parkinson disease.**

Aerobic Exercise: Evidence for a Direct Brain Effect to Slow Parkinson Disease Progression
Ahlskog, J. Eric
Mayo Clinic Proceedings, Volume 93, Issue 3, 360 - 372

Why is Exercise Important?

- Conclusion from this evidence: Regular aerobic-type exercise tending to lead to fitness is the single strategy with compelling evidence for slowing Parkinson disease progression. All patients with Parkinson disease should be encouraged to engage in regular such exercise.

Aerobic Exercise: Evidence for a Direct Brain Effect to Slow Parkinson Disease Progression
Ahlskog, J. Eric
Mayo Clinic Proceedings, Volume 93, Issue 3, 360 - 372

Why is Exercise Important?

Neurorehabilitation and Neural Repair
Volume 23 Number 6
July/August 2009 600-608
© 2009 The Author(s)
10.1177/1545968308328726
http://nnr.sagepub.com

Forced, Not Voluntary, Exercise Improves Motor Function in Parkinson's Disease Patients

Angela L. Ridgel, PhD, Jerrold L. Vitek, MD, PhD, and Jay L. Alberts, PhD

Background. Animal studies indicate forced exercise (FE) improves overall motor function in Parkinsonian rodents. Global improvements in motor function following voluntary exercise (VE) are not widely reported in human Parkinson's disease (PD) patients. *Objective.* The aim of this study was to compare the effects of VE and FE on PD symptoms, motor function, and bimanual dexterity. *Methods.* Ten patients with mild to moderate PD were randomly assigned to complete 8 weeks of FE or VE. With the assistance of a trainer, patients in the FE group pedaled at a rate 30% greater than their preferred voluntary rate, whereas patients in the VE group pedaled at their preferred rate. Aerobic intensity for both groups was identical, 60% to 80% of their individualized training heart rate. *Results.* Aerobic fitness improved for both groups. Following FE, Unified Parkinson's Disease Rating Scale (UPDRS) motor scores improved 35%, whereas patients completing VE did not exhibit any improvement. The control and coordination of grasping forces during the performance of a functional bimanual dexterity task improved significantly for patients in the FE group, whereas no changes in motor performance were observed following VE. Improvements in clinical measures of rigidity and bradykinesia and biomechanical measures of bimanual dexterity were maintained 4 weeks after FE cessation. *Conclusions.* Aerobic fitness can be improved in PD patients following both VE and FE interventions. However, only FE results in significant improvements in motor function and bimanual dexterity. Biomechanical data indicate that FE leads to a shift in motor control strategy, from feedback to a greater reliance on feedforward processes, which suggests FE may be altering central motor control processes.

Ridgel AL, Vitek JL, Alberts JL. Forced, not voluntary, exercise improves motor function in Parkinson's disease patients. Neurorehabil Neural Repair. 2009 Jul-Aug;23(6):600-8. doi: 10.1177/1545968308328726. Epub 2009 Jan 8. PMID: 19131578.

What are the Benefits of Exercise?

Improvements in:

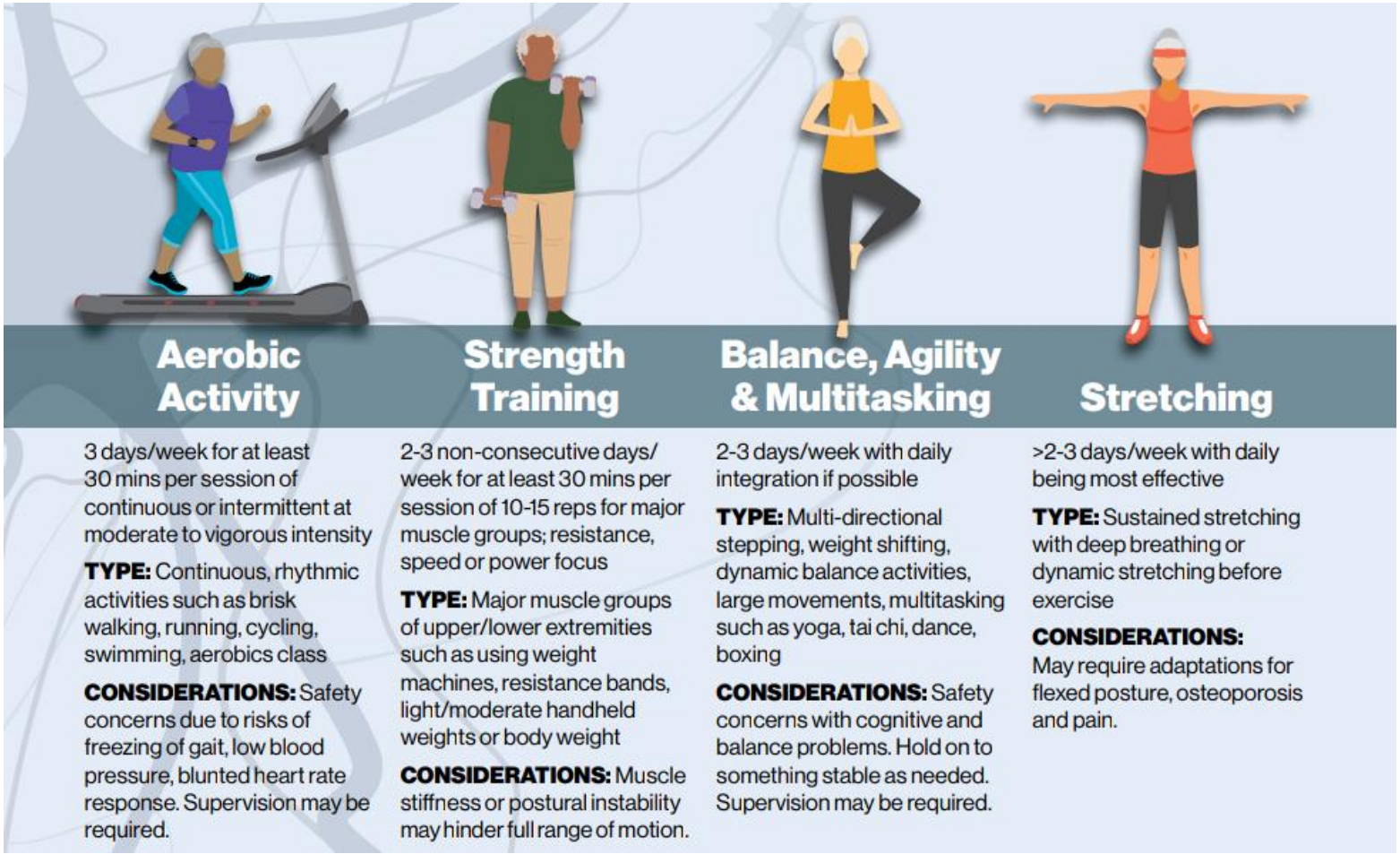
- Gait and balance
- Flexibility and posture
- Working memory and decision making
- Attention and concentration
- Motor coordination
- Endurance
- Quality of sleep

Reduction in:

- Falls
- Freezing of gait
- Depression / anxiety

Exercise is NEUROPROTECTIVE!

Parkinson's Exercise Recommendations



Aerobic Activity

3 days/week for at least 30 mins per session of continuous or intermittent at moderate to vigorous intensity

TYPE: Continuous, rhythmic activities such as brisk walking, running, cycling, swimming, aerobics class

CONSIDERATIONS: Safety concerns due to risks of freezing of gait, low blood pressure, blunted heart rate response. Supervision may be required.

Strength Training

2-3 non-consecutive days/ week for at least 30 mins per session of 10-15 reps for major muscle groups; resistance, speed or power focus

TYPE: Major muscle groups of upper/lower extremities such as using weight machines, resistance bands, light/moderate handheld weights or body weight

CONSIDERATIONS: Muscle stiffness or postural instability may hinder full range of motion.

Balance, Agility & Multitasking

2-3 days/week with daily integration if possible

TYPE: Multi-directional stepping, weight shifting, dynamic balance activities, large movements, multitasking such as yoga, tai chi, dance, boxing

CONSIDERATIONS: Safety concerns with cognitive and balance problems. Hold on to something stable as needed. Supervision may be required.

Stretching

>2-3 days/week with daily being most effective

TYPE: Sustained stretching with deep breathing or dynamic stretching before exercise

CONSIDERATIONS: May require adaptations for flexed posture, osteoporosis and pain.

Exercise Recommendations

- Aerobic Exercise
  - 3 days/week
  - >30 minutes
- Strength Training
  - 2-3 days/week
  - >30 min
- Balance, agility +multi-tasking
  - >2-3 days/week, daily if possible
- Stretching
  - >2-3 days/week daily if possible

A Typical Week

Monday: Aerobic exercise – Treadmill, cycling, power walk outside

Tuesday: Strength training, Dance, Yoga, Tai Chi, Boxing

Wednesday: Aerobic exercise - Treadmill, cycling, power walk outside

Thursday: Pickleball, Swimming, softball

Friday: Strength training, Dance, Yoga, Tai Chi, Boxing

Saturday: Aerobic exercise – Treadmill, cycling, power walk outside

Sunday: Rest/Stretch/strength training/keep moving

Overcoming Barriers to Exercise

- When it may be time to schedule a Physical Therapy Evaluation
  - Limitations in mobility
  - Pain
  - Balance issues or falling
  - Freezing of gait
  - Low confidence or unmotivated
  - Deconditioned

"I just don't know where to start"

Summary – What you can do NOW!

- Exercise is medicine!!!
- Exercise with a professional who specializes in the treatment of Parkinson's
- Follow recommendations supported by current research
  - at least 150 mins / week
- Consider starting with a physical therapy evaluation, work towards community exercise class
- Don't go at it alone, it takes a village!

Baseline Time

30 Second Sit to stand

Age	Fall Risk		Normal	
	Men	Women	Men	Women
60-64	<14	<12	17	15
65-69	<12	<11	17	15
70-74	<12	<10	15	14
75-79	<11	<10	15	14
80-84	<10	<9	13	12
85-89	<8	<8	13	12
90-94	<7	<4	10	10

Amy Feder
Social Worker

- LCSW, CDP
- Masters of Social Work, NYU, 1994
- Focus on providing emotional support and education to families, caregivers and loved ones dealing with Parkinson's Disease
- Leads monthly support groups for caregivers of Parkinson's patients
- Expert Topics:
  - Mental Health
  - End of life planning

Psychological Changes with PD

Affected Non-Motor Symptoms:

- Memory Loss
- Cognition changes
  - Attention
  - Retrieving information
  - Dual Tasking
- Emotional Changes
  - Anxiety
  - Impulsivity
  - Depression
  - Apathy
- Physical Changes

Adaptations:

- Making adaptations to ADLs
- Memory/Cognition strategies
- How to recognize when you need help
- Self care

End of Life Planning

- Advanced Directives
- File of Life
  - Medical information accessible
- Critical Care Documents
  - Health Care Proxy
  - Power of Attorney

Summary – What can you do NOW!

- Join a support group
- Seek out mental health professional
- Plan for end of life
  - Social Worker
  - Attorney
  - Family meeting

Baseline Time

- Walking
  - Gait Speed
- Strength
  - 30 Second Sit to Stand
- Balance
  - Turning 360°
- Self Efficacy
  - SPDD
- Pro-PD score https://educationismedicine.com/pro-pd
- Self Assessment PD Disability Scale
- **Paper Hand out for baselines, take photos to log it. Name, DOB, Year of DX**

Catherine Peru
Nursing

- RN, BSN
- Diverse healthcare background lending to comprehensive observation, assessment and management of wellness status
- Expert Topics: Medication management of PD

Nurse's Role in PD

- To support people with the clinical aspect of their PD diagnosis and to help manage medication, so they get the best results with least side effects.

Medications with PD

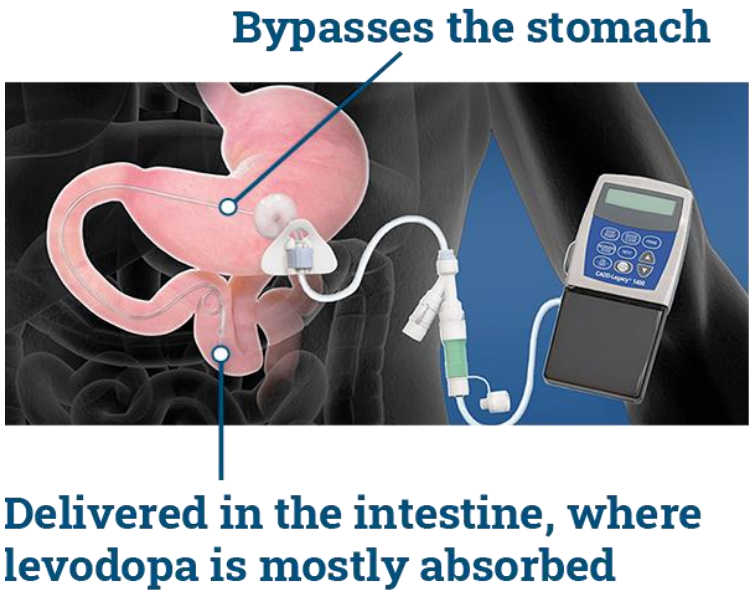
- Prescribed by
  - PCP
  - Neurologist
  - Movement Disorder Specialists
  - There is no one best mix of PD medicines. You and your doctor will figure out what is the best for you.
  - Carbidopa/Levodopa remains the gold standard
  - Dopamine agonists act like dopamine in the brain. They include pramipexole (Mirapex), rotigotine (Neupro), and ropinirole (Requip)
  - Amantadine works by raising the amount of dopamine that your brain cells can use.

Medication Considerations

- Medication side effects may include drowsiness, dizziness, and orthostatic blood pressure changes
- Monitor for adverse effects: CNS changes, urinary retention, GI depression, decreased sweating, etc.
- Avoid using PD medication with OTC cold medications or alcoholic beverages.
- Compliance with drug therapy.

When Medications aren't Enough

- Surgical options - reserved for those who have exhausted medication treatment
- DBS - most effective for people who experience disabling tremors, wearing-off spells, and medication-induced dyskinesias.
- Duopa -



Summary – What can you do NOW!

- Exercise is medicine
- Medicine is medicine too - Integrate
- Know the names of medications and how you take them. Know the generic and brand names and doses
- Take medications as prescribed
- Have a routine for taking medications. Take them at the same time each day. Set an alarm if needed
- Keep a medication record and if you miss a dose don't panic, take it as soon as you remember. But if it's almost time for your next dose, skip the missed dose and return to your regular medication schedule.
- Take extra medicine with you when you travel
- Refill your prescriptions before you run out
- Physical activity may help your body digest and absorb your medication.
- We will work as a team to integrate all aspects of PD
- Our goal is for you to be your best.

Garrett Walkup
Spiritual Care Coordinator

- Emotional and spiritual support for patients and families
- Expert Topics:
  - Emotional and spiritual support for Parkinson's patients and their caregivers
  - Grief, loss and bereavement support for individuals and small groups

Role of Chaplain in PD

- Ordained Pastor
- Support group leader
- Chance to discuss life, passions, who you are (more than just PD)
- Support for care-partners
- Bereavement

Spiritual Health and Well-Being

We need to care for our spirit (soul) the way we need to care for our body and mind. Having a spiritual practice connects us to what is sacred, beautiful, and meaningful in our lives.

PD impacts your body and mind, but it does not touch who you are, what you believe or what you are passionate about.

Having to confront our mortality due to a terminal diagnosis can send us on a journey of questions…

“Why me?”

“Where is God?”

“What do I believe about what is happening to me?”

Having a spiritual practice can bring calm in the storm.

Summary – What can you do NOW!

- Worship services either in-person or online
- Sacred traditions: singing & music, receiving communion, reciting mantras or corporate prayers
- Daily time of meditation, reflection (journaling if you are able), personal prayer
- Regular opportunities to express your thoughts and emotions such as a support group or friend meet-up
- Identify what gives you peace and joy. What do you find holy and beautiful?

Kristine Greco
Physical Therapist

- PT, MPT, cert. LSVT BIG, CCVR
- Treats patients at the RVNAhealth Rehabilitation & Wellness Center and in the home health setting
- Focused on a patient centered and evidence-based approach to rehabilitation and wellness
- Leads LSVT BIG for LIFE group exercise classes
- Holds certifications in Vestibular Rehabilitation, Neurologic Rehabilitation, and Fall Prevention
- Expert Topics: Exercise prescription, Balance assessment, Fall prevention, Patient and Care Partner Education

Physical Therapist's Role in PD

- Physical Therapists are an integral part of the care team for PWP.
- Physical Therapists are trained to relate objective findings on strength, balance, flexibility, endurance, and gait to impact on function.
- Evaluation findings are used to create individualized plans of care -- to prescribe appropriate exercises / customize LSVT BIG program, recommend modifications to ADLs, and educate clients and care partners.

LSVT BIG

- LSVT LOUD (Lee Silverman Voice Treatment) was developed first, from 1987-89, as an exercise-based approach to improve speech intelligibility in PWP.
- Approach was later expanded to include a Physical and Occupation Therapy program called LSVT BIG to address fine and gross motor functions.
- Program is evidence-based and intended to be delivered at a 4x/week frequency for 4 weeks, then performed long-term 1-2x/day. Tune-ups occur as necessary.

LSVT BIG

- Based on principals of NEUROPLASTICITY.

- Key concepts of LSVT BIG include
  - Single Target: Amplitude
  - Mode: High Intensity and High Effort
  - Goal: Calibration
  - Tasks: Salient

LSVT BIG

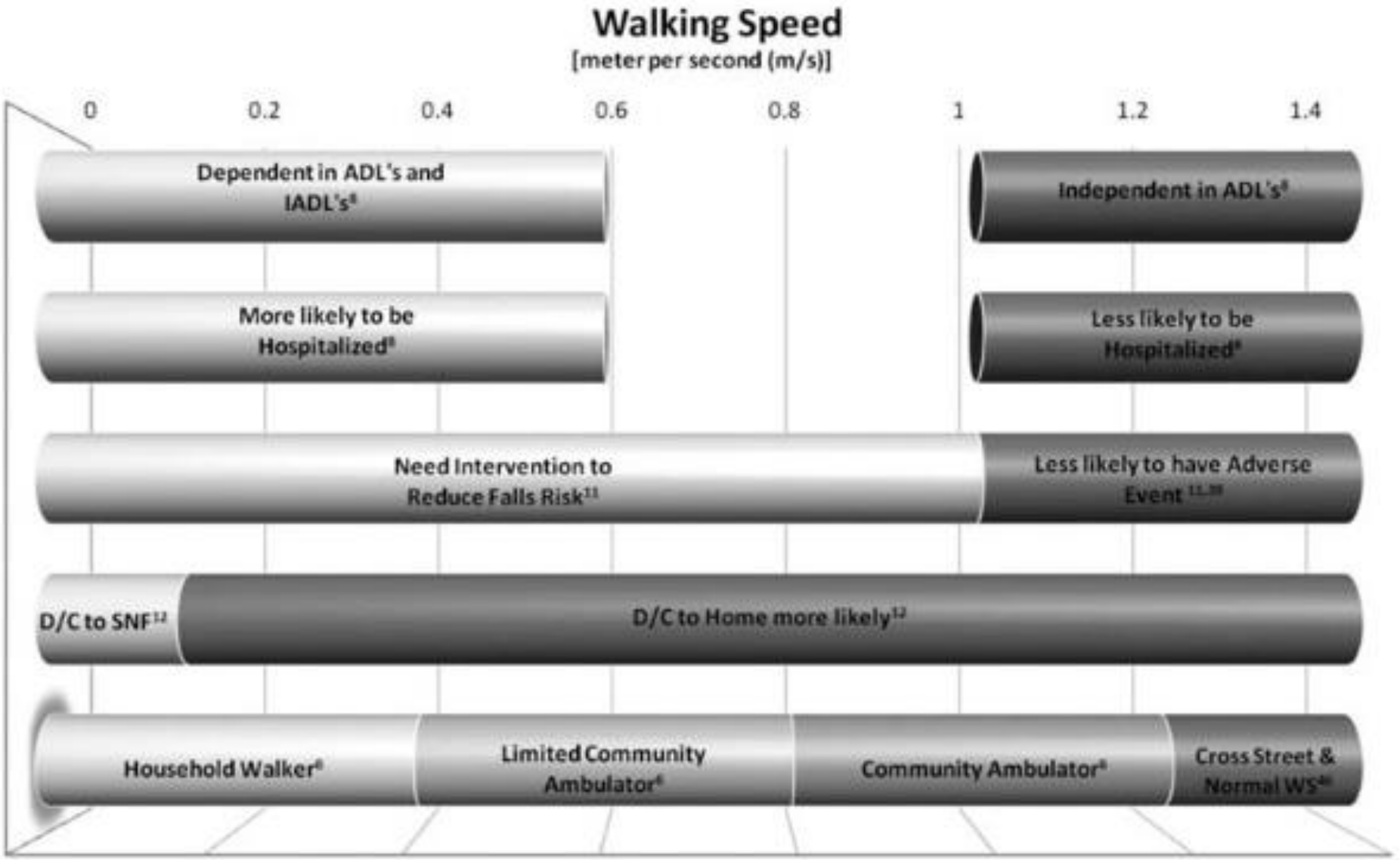
Structure of Program

- Seven Maximal Daily Exercises
- Three to Five Functional Component Tasks
- One Hierarchy Task
- BIG Walking

Summary – What can you do NOW!

- Take notice of how you are moving and take control -- BIG Posture, BIG Walking, STS
- Participate in exercise and activities that you enjoy on a daily basis -- aerobic, strength, balance, and flexibility.
- Pursue a physical therapy evaluation to identify deficits and develop an individualized exercise program to maintain and / or improve function
- It is never too early or too late to get started!

Baseline Time



Baseline Time

Gait Speed

- Norms:
- 50’s: 1.39-1.4m/s
- 60’s: 1.3-1.36 m/s
- 70’s: 1.27-1.33m/s
- 80’s: .8 m/s
- 90’s: .7 m/s

Megan Laber
Physical Therapist Assistant

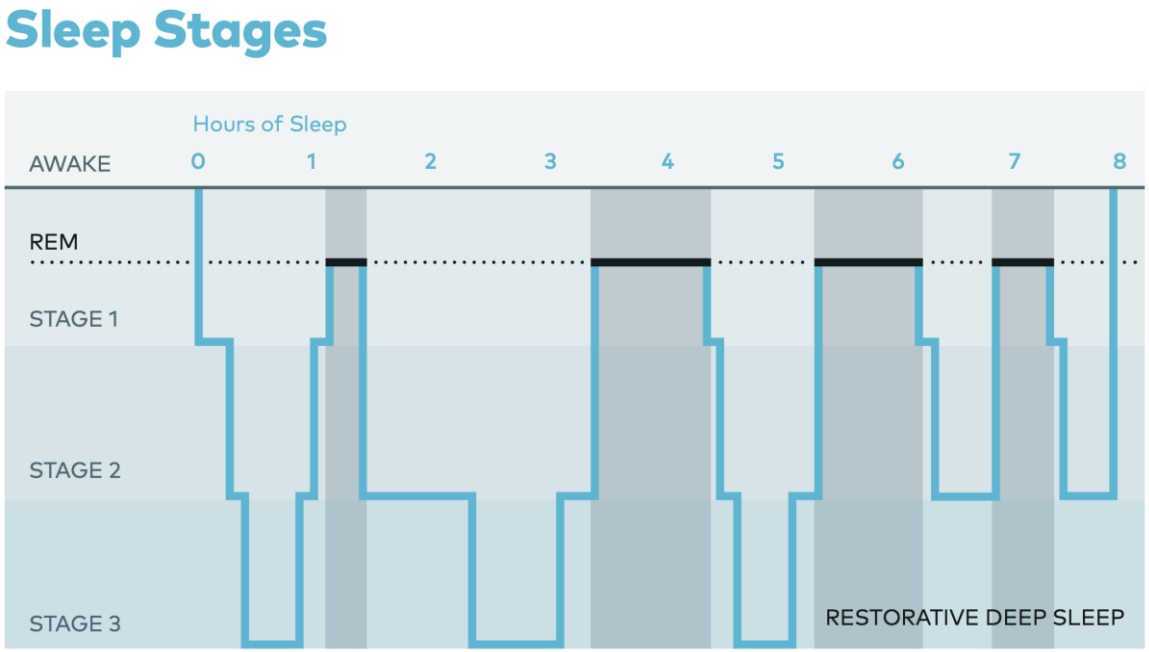
- PTA, LSVT BIG, Cert Running Gait Analyst, CPT
- Assist in exercise prescription & instruction
- Current personal caregiver to a family member with Parkinson's disease
- Expert Topics: Care Partner Education, Quality of Sleep, Exercise Interventions, Balance

Physical Therapist Assistant's Role in PD

- Implement patient care, obtain data and collaborate with PT
  - Apply PT interventions and treat within PT plan of care
- Assist in assessment of strength, balance, flexibility, gait, and overall function
- LSVT BIG
- Sleep Hygiene
- Care Partners

Sleep Hygiene

- Non-motor symptom
- Importance of sleep!
- Habits that promote **quality** sleep
- Circadian rhythms
- REM
- Non-REM
  - Stage 1, 2, 3



Sleep Disorders

- 80% of people with PD report poor sleep[1]
  - Insomnia
  - REM sleep behavior disorder (RBD)
  - Sleep apnea
  - Restless legs syndrome (RLS)
  - Excessive daytime sleepiness (EDS)

1. *Sleep - A Mind Guide to Parkinson's Disease*. 2020.

Summary- What can you do NOW!

- Strive for 8 hours a night
- No screens in the bedroom
- The bedroom is for two things only!
- Avoid caffeine in the afternoon
- Keep a cool temperature in the bedroom
- Don’t exercise too close to bedtime, but exercise helps sleep!

- Limit liquids after 8pm to decrease bathroom trips at night
- Consistency is King! Go to bed, wake up and take meds on the same schedule
- Dark room at night, lots of light in the AM

Summary- What can you do NOW!

- Meet with healthcare provider
  - Sleep study
  - Treatment
  - Participate in research study
- Discuss medications and side effects of current medications
- Meet with PTA, RN, LCSW at the Parkinson's Center

Care Partners

- Care Partners vs Caregivers
- Essential!
- YOUR needs:
  - PD education
  - Time management
  - Self-care, health and respite
  - Support team
  - Your relationship with the person with PD
  - Medical, financial and care decisions
  - Community resources

Care Partners

- Early
  - Organize medical information
  - Communication
  - Encourage exercise and activity
  - Simple cues, demonstration
  - Non-motor symptoms
  - Positive feedback and encouragement
  - Care for YOU- mental health
- Late
  - Transfers, equipment
  - Prevent falls
  - Care for YOU- mental health, respite care

Care Partner Self-Assessment

Rate each item below from 1 (almost always) to 5 (never) according to how much of the time each statement applies to you. Write the date above so you can track your wellbeing over time.

1 = ALMOST ALWAYS
2 = FREQUENTLY
3 = OCCASIONALLY
4 = RARELY
5 = NEVER

1. I exercise on a regular basis.	1 2 3 4 5
2. I make and keep preventive and necessary medical and dental appointments.	1 2 3 4 5
3. I have a job or regular volunteer activity that is gratifying.	1 2 3 4 5
4. I do not use tobacco products.	1 2 3 4 5
5. I do not use alcohol or drugs.	1 2 3 4 5
6. I get an adequate amount of sleep each day.	1 2 3 4 5

Care Partner Self-Assessment

7.	I have a hobby or recreational activity I enjoy and spend time doing.	1 2 3 4 5
8.	I eat at least two to three balanced meals a day.	1 2 3 4 5
9.	I have at least one person in whom I can confide (tell my problems, discuss my successes).	1 2 3 4 5
10.	I take time to do things that are important to me (e.g., church, garden, read, spend time alone).	1 2 3 4 5
11.	I do not have problems with sleeplessness or anxiety.	1 2 3 4 5
12.	I have personal goals and am taking steps to achieve them.	1 2 3 4 5

= Total Score

12-24: Excellent job!
25-36: Room for improvement
37-48: Poor job taking care of yourself, moderate risk personal health problems
48-60: Extremely high risk for personal health problems

Summary - What can you do NOW!

- Examine areas of struggle & ask for help
- Talk directly to healthcare provider
- Attend appointments with person with PD
- MD, PT, OT, SLP, etc.
- Meet 1-on-1 with myself
  - Amy, LCSW
  - Cathy, RN

Sarah Triano
Occupational Therapist

- CERT OTR/L, LSVT BIG
- Treats Parkinson's Center patients at RVNAhealth Rehabilitation and Wellness Center
- Teaches Boxing class in PD Bootcamp
- Expert Topics: Tremor management, Fine/Gross motor coordination, Stretching/Strengthening, ADL/IADL management, Handwriting

Occupational Therapist's Role in PD

Early

- Self-management
- Maintenance of participation
- Performance enhancement

Mid

- Adaptation
- Compensation
- Environmental modifications
- Preserve independence and engagement

Late

- Environmental modifications
- Safety & comfort
- Care partner training
- Meaningful engagement

Impact of Symptoms on Function: Rigidity & Tremor

- Decreased dexterity, Fine motor impairments
- Impaired manipulation, difficulty with sustained tasks
- Impaired functional reach
- Difficulty buttoning, writing/typing, cutting food, retrieving items from wallet, cell phone use
- Increased time for task completion
- Decreased independence/occupational deprivation

ADL/iADL considerations

- **Fine Motor/Upper Arm Impairments**
  - Limb-kinetic apraxia- decreased coordination
  - Bradykinesia
  - Tremor
  - Reduced hand/UE strength
  - Rigidity
- **Decreased Functional Balance/Freezing/Festination**
- **Environmental set up**

Summary – What can you do NOW!

- Assess your writing
  - Does it start big and end small? Practice writing BIG
- Increase your hand strength
  - Theraputty
  - Digi squeeze ball
  - Hand grippers
  - Opening and closing container
- Assess and increase your Hand coordination
  - Playing card: dealing, sorting, shuffling, flipping over
  - Puzzles
  - Writing a letter or email to a loved one/journaling
- OT Individualized Evaluation
  - Treatment sessions focused on a specific set of goals meaningful to you utilizing evidence-based intervention 2-4x a week: one to one basis
  - Individualized Home exercise plan tailored specifically to your needs
- Home assessment- recommendations
- Participation in group exercise classes by trained professionals

Susan DiGregorio
Speech and Language Pathologist

- M.A CCC-SLP, LSVT LOUD
- 12 years' experience working with adult population with focus on cognition, language, speech and swallowing impairments following neurological injury as well as progressive disease.
- Experience working within multi and interdisciplinary teams to maximize outcomes for patients with Parkinson's Disease
- Expert Topics: Speech, Voice, Language, Cognition and Swallow function

Speech and Language Pathologist's Role in PD

- Evaluates:
  - Speech
  - Voice
  - Swallowing
  - Cognition
  - Language
- Provides specific, individualized treatment to address changes

PD Affects your Speech

- Hypokinetic Dysarthria
- Quieter or weaker voice
- Hoarse voice
- Slurred speech
- Fast speech
- Sounds run together

Summary – What can you do NOW!

- Talk LOUDER!
- Speak in shorter phrases
- Look at the people you are talking to Before you speak,
- Get the attention of the person you want to talk to
- Talk in a quiet location
- Plan conversations for when you have more energy
- THINK LOUD!
- SLP evaluation for voice exercises and strategies to improve your communication

What is LSVT LOUD?

- 30 years of experience, level 1 evidence
- LSVT LOUD is a standardized speech treatment protocol that is customized to the unique communication goals of each client.
- Increased vocal loudness
- Improved articulation and speech intelligibility
- Improved intonation
- Improvements in facial expression
- Changes in neural functioning related to voice and speech

PD Affects your Swallowing

- Choking, coughing, throat clearing when you eat or drink
- Voice sounds “wet”
- Many swallows to “get the food down”
- You have food left over in your mouth after swallowing
- Food/liquid leaks out of your mouth
- If you have chest congestion or fevers, see SLP or MD to rule out infection

Summary – What can you do NOW!

- Focus on eating, one thing at a time
- Take small bites and sips, one at a time
- Chew your food well
- Sit up straight when you eat
- For each bite or sip you take, swallow two times
- Be careful using straws.
- Swallow pills, one at a time, with a spoonful of mashed bananas to help them go down
- If you notice coughing or throat clearing when you eat or drink, tell your doctor

Summary – What can you do NOW!

- Clinical evaluation of swallow function with a skilled therapist
- Referral for instrumental evaluation of swallow function (ex. Modified Barium swallow study, Fiberoptic endoscopic evaluation of swallowing) to gather baseline date and better inform treatment
- Education for use of *SAFE SWALLOW STRATEGIES and EXERCISES*

PD Affects your Cognition

- Neurochemical signal changes
- Lewy Bodies
- Other causes include co-existing strokes or Alzheimer's disease pathology.
- Mild cognitive impairment occurs in about 20-50% of PwP
- About 40% of PwP develop dementia

PD Affects your Cognition

- Slower thinking and information processing
- Difficulty focusing attention and multi-tasking
- Decline in working memory and short-term memory
- Difficulties with executive function (planning ahead, problem-solving, reasoning and sequencing)
- Difficulties with visuospatial function (navigating in a new environment, motor planning)
- Difficulties finding the words you want
- Losing train of thought while speaking
- Social isolation and avoidance

Summary – What can you do NOW!

- Stimulate your brain
  - Have conversations
  - Challenge yourself cognitively (math, crosswords, sudoku)
  - Go through picture albums and talk about memories
  - Exercise
- See an SLP:
  - Evaluates Cognitive-linguistic function
  - Collaborates to develop meaningful and functional goals
  - Prescribe treatment programs with focus on compensatory strategies and exercises to stimulate brain function

Sherrye Platt
Music Therapist

- MA, MT-BC
- Provide care for patients utilizing evidence-based music therapy and a person-centered, humanistic approach
- Leads education series for RVNAhealth on Music and Brain Health
- Expert Topics: Music for Parkinson's Disease, Dementia, Cognitive and Physical Wellness

Tammy Strom
Music Therapist

- MA, MT-BC
- Board certified in music therapy, with a master's degree in expressive therapies with a concentration in music therapy and mental health counseling.
- Provide care for patients utilizing evidence-based music therapy and a person-centered, humanistic approach

Music Therapist's Role in PD

- Knowledge of the current research of the effects of music therapy in gait control, balance, mood improvement, and vocal quality.
- Assess physical, social, and emotional needs in people diagnosed with Parkinson's Disease
- Implement evidence based music therapy interventions to meet each person's individual needs and help them reach their goals

Music

- Music therapy improves gait velocity, stride length and cadence compared to the control group.
- Music provides rhythmic cues that facilitate motor coordination, and improve walking ability
- Provides a non-pharmacological approach to complement traditional treatments for PD

Source: "Music Therapy for Gait Impairment in Parkinson's Disease: A Controlled Randomized Study" by Filipe B. Rodrigues et al. (2021) in Frontiers in Psychology.

Summary – What can you do NOW!

- Sing
- Dance
- Listen to music that elevates your mood
- Play an instrument
- Participate in a drum circle
- Talk to your loved ones about your favorite music

Welcome to the Parkinson's Center
The Mission:

The RVNAhealth Parkinson's Center is a community based interprofessional center serving individuals and their families with Parkinson's Disease through support, education, therapy, social engagement, exercise, and lifelong wellness programs. Our goal is to be a resource for all People with Parkinson's (PWP), their caregivers, and medical teams to meet their educational, emotional, and physical needs.

Why do we need a Parkinson's Center?

- Better and easier access to care
- Become confident at managing your symptoms
- Support for all stages
- A disease that effects so many aspects of life needs an interprofessional team

Components

- Therapy
- Exercise classes
- Community Programming
- PD Bootcamp

Components

- **Therapy**
- Exercise classes
- Community Programming
- PD Bootcamp

- All therapists are LSVT BIG/LOUD certified
- Parkinson's Foundation Team Training
- Physical Therapy
- Occupational Therapy
- Speech and Language Pathology
- In home or at RVNAhealth Rehabilitation and Wellness Center

Components

- Therapy (PT/OT/SLP)
- **Exercise classes** 
- Community Programming
- PD Bootcamp

- Strength and Beyond
- Balance and Beyond
- LSVT BIG
- LSVT LOUD

Components

- Therapy (PT/OT/SLP)
- Exercise classes
- **Community Programming**
  - **Lecture Series**
  - Support Groups
  - Social Activities
- PD Bootcamp

- Nutrition
- Speech/Swallowing/ Cognition
- Tremor management
- "Ask the Experts"
- Medical vs Surgical Management
- Exercise and LSVT
- Speakers:
  - Dr. Bonwetsch
  - Dr. Machado
  - Dr. Rodriguez

Components

- Therapy (PT/OT/SLP)
- Exercise classes
- **Community Programming**
  - Lecture Series
  - **Support Groups**
  - Social Activities
- PD Bootcamp

- PWP and their caregiver combined
- PWP separate from caregiver
- Last Wednesday of each month, 2:00-3:00 pm

Components

- Therapy (PT/OT/SLP)
- Exercise classes
- **Community Programming**
  - Lecture Series
  - Support Groups
  - **Social Activities**
- PD Bootcamp

- "Cooking with PD"
- Holiday Dance Party
- Sing-a-long/Choir
- Olympic games
- Brain Games
- Outdoor walks/hikes
- Field Day
- Trips
- Any ideas?!

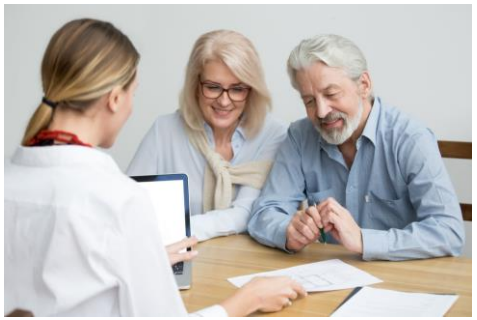
Components

- Therapy (PT/OT/SLP)
- Exercise classes
- Community Programming
- **PD Bootcamp**

Goal: to provide an individualized program for each PWP to best manage their disease progression

PD Bootcamp

- Six participants
- Eight weeks
- Group lecture
- Workbook
- Twice a week exercise class



PD Bootcamp

One-on-one sessions with each discipline to discuss individualized approach to:

- Exercise Prescription
- Fine motor assessment
- Strength/Flexibility assessment
- Balance assessment
- Medication management
- Mental health
- Sleep
- Speech/Swallowing
- Cognition
- Diet
- Pelvic Health
- Driving Assessment
- End of life planning

Our Parkinson's Center Community

- Interprofessional Team
- RVNAhealth Employees
- People with Parkinson's
- Caregivers/Family members

- Medical team
  - Primary Care Physicians
  - Neurologists
  - Movement Disorder Specialists
- Resources
  - Abbott
  - APDA

Accessibility

- Currently share space with RVNAhealth
  - Hosting events/support groups
  - Therapy/Counseling on-site
  - Exercise classes
- Parkinson's Center general questions: PCInfo@rvnahealth.org
- Parkinson's Specific questions to the team through ParkinsonsCenter@rvnahealth.org
- Website www.rvnahealth.org/parkinsonscenter/
- Facebook group
- Voicemail 203-438-5555 x 1082
- Events via zoom as well
- Eventually RVNAhealth Van transportation

Meet the Team - Leaders

- Gigi Weiss – Parkinson's Center Director
- Kate Campbell – Parkinson's Center Program Manager
- Andrea de Lange – Parkinson's Center Clinical Lead

Meet the Team – Clinical Team

- Amy Feder, Social Worker
- Cathy Peru, Nursing
- Garrett Walkup, Chaplain
- Kris Greco, Physical Therapist
- Megan Laber, Physical Therapist Assistant
- Monica Marcello, Registered Dietician
- Sarah Triano, Occupational Therapist
- Sherrye Platt, Music Therapist
- Susan DiGregorio, Speech and Language Pathologist
- Tammy Strom, Music Therapist

Upcoming Dates

- May 17, 12:00 “Updates on Treatments for Parkinson’s Disease” Dr. Bonwetsch
- Support Groups starting May 31st, 2pm, monthly
- Watch new MJF movie?
- Shrinking?
- Book Club – Dean Scaros Reflections on a Simple Twist of Fate
- Any ideas – email us

Thank You For Attending

This program is brought to you by the generosity of our donors.

To make a donation, or to learn more about RVNAhealth, please visit RVNAhealth.org