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The Basics of Parkinson's Disease & The Parkinson's Project

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Community Engagement Manager

What is Parkinson's?

- Movement Disorder affecting 1% of the population over 60
- Chronic, progressive neurological disorder
- No cure and no way to halt progression
- Treatments focus on symptom management

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Who Gets Parkinson's?

- Approximately 1 million Americans
- 60,000 new cases diagnosed each year
- Worldwide numbers could be up to 10 million
- Average age of onset is 65
- Risk increases with age
- 15% of people with Parkinson's are diagnosed under the age of 60

Last updated in 2017

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Why don’t we know exactly how many people have Parkinson’s?

- Incidence rates
- Death certificates
- 1960s study in Mississippi
- NIH & CDC

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What Causes Parkinson's?

- Genetic vs. Environmental?
  - Genetic Biomarkers
    - Mutations in the LRRK-2 or Parkin-9 genes
  - Environmental Cases
    - Heroin Users in CA in 80s used a batch of heroin laced with MPTP
    - Veterans who were exposed to agent orange and develop PD don't have to prove connection to receive benefits from the VA
    - Roundup weed killer
  - **Genetics is the seed; the environment (weather) determines if it grows or not**

Updated 08.03.20

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Four Primary Motor Symptoms

1. Resting Tremor
2. Bradykinesia (Slowness of Movement)
3. Rigidity
4. Postural Instability

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Four Primary Motor Symptoms

1. Resting Tremor
   - 70% of patients experience resting tremor
   - Often begins on one side, which remains most affected
   - Fatigue and stress worsen tremor

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Four Primary Motor Symptoms

2. Bradykinesia
   - Slow Movement
   - Loss of spontaneous, automatic movement
   - Unpredictable

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Four Primary Motor Symptoms

3. Rigidity
   - Stiffness of arms, legs, trunk
   - Affects all muscles
   - Limits speed of movement
   - Can sometimes lead to discomfort or pain

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Four Primary Motor Symptoms

4. Postural Instability
   - Unstable when standing upright
   - Can cause leaning, can lead to falling
   - Does not respond well to medications

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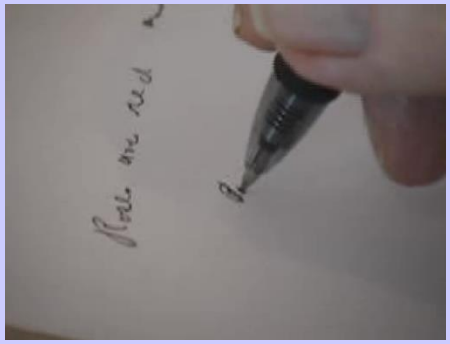
Other Motor Symptoms

- Micrographia (Small, cramped handwriting)
- Masked facial expressions
- Low speech volume
- Difficulty swallowing
- Shuffling Gait
- Freezing



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Cognitive & Non-Motor Symptoms

- Slowed thinking
- Memory problems
- Depression
- Anxiety
- Fatigue
- Sleep disturbances
- Constipation
- Urinary urgency and frequency

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Progression of Symptoms

Medicine

DBS

Consistent Motor Control with Medicine

Signs of levodopa "wearing off"

Dyskinesia, "On-Off" Fluctuations

Dopamine Non-Responsive Symptoms: Postural Instability, Freezing of Gait, Speech, Swallowing

Early Stage

Mid Stage

Last Stage

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Carepartner Issues

- Changing roles
- Sleep deprivation and exhaustion
- Isolation
- For many folks, especially young onset, balancing work, children, caregiving
- Self-care is critical

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Healthcare Team & Treatment Plan

- Medical Care
  - Primary Care Provider
  - Neurologist/Movement Disorder Specialist
- Occupational Therapy
- Physical Therapy
- Speech Therapy
- EXERCISE!
- Care plans change over time as the disease progresses
- Independence and staying active are important

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Tips for Providers

1. Give people with Parkinson's more time to do things
   - Transitions between exercises/poses
   - Walking
   - Using the restroom
   - Thinking and talking
2. Be flexible
   - Parkinson's does get worse over time
   - PWPs may need to take medications during class, etc.
3. Stress, anxiety and depression can all make symptoms worse

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Tips for Providers

4. Promote routine physical activity and exercise
   - Remind PWPs of the “Use it or lose it” philosophy
   - Help folks understand how exercise helps with stress and mood
   - Lots of resources and options available!
5. Understand the disease
   - Knowledge of Parkinson’s is important so that you can best help people coming to your programs
   - Keep up on research

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The Parkinson's Project

The Parkinson's Project

In collaboration with the University of Washington Medical Center, Veteran Affairs of Seattle, and Rep. Eric Pettigrew, Northwest Parkinson's Foundation presents *The Parkinson's Project*

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The Parkinson's Project

Northwest Parkinson's Executive Director, Melissa Tribelhorn, wrote this Parkinson's Project with the intention to gather better data on how many people are living with Parkinson's in Washington State

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The Parkinson's Project

This project was written in two parts;

First, to gather Medicaid data for the past 3 fiscal years to see who's been billed for Parkinson's disease (all within HIPAA compliance), and identify the number of people with Parkinson's in King County by race (specifically African/African-American)

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The Parkinson's Project

Second, provide outreach, education and social services to those within the 37th district, focusing on African/African-American communities

Jordan's role: I'm here to provide education on Parkinson's, get folks connected to programs & services and specialty healthcare, and learn about barriers faced in accessing specialty healthcare

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The Parkinson's Project

Progress: trainings with local organizations, mailings have gone out, putting together a video interview with PP Advocate

Hurdles: COVID-19 has made outreach work challenging! Trying to get meetings, trainings, education sessions in-person is tricky.

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NW Parkinson's Programs

- HOPE Conferences® tailored to local communities
- The Weekly Email newsletter
- Online programming: Yoga, Mindfulness, Feldenkrais Method, education
- Dance for PD®
- NW Parkinson's Lending Library
- NWPF.org

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NW Parkinson's Services

- Individualized Navigation Sessions with Master's level Social Workers
- Advocacy
- General Neurology and Movement Disorders Specialist outreach
- HOPE Kits (geographically tailored resources) for newly & recently diagnosed
- Support Group Facilitation Workshops

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Community Partnerships

Opportunities to provide Parkinson's education

- Presenting at Staff Meetings
- Having a (virtual) table at Health Fairs & other programs
- Speaking at community gatherings, meetings, programs
- Having a regular table to be available to community members at community centers and hubs

Ways to support Northwest Parkinson's

- Share NW Parkinson's cards
- Share Parkinson's Project flyers
- Make Patient Referrals

The Parkinson's Project

Are you or someone you know living with Parkinson's disease?

Are you interested in getting connected to the appropriate medical professional for the personalized care necessary for living well with Parkinson's?

Northwest Parkinson's Foundation is partnering with the University of Washington and the VA to **better connect South King County communities of color** with one-on-one social services and health care professionals. We're here so no one walks the Parkinson's journey alone.

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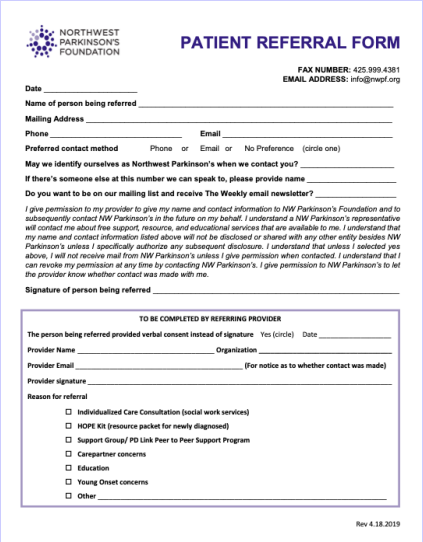
If you're interested in learning more about the Parkinson's Project and the resources offered by NW Parkinson's, contact Jordan Whitley at:

206.946.6520 or Jordan@NWPF.org



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PATIENT REFERRAL FORM

FAX NUMBER: 425.999.4381
EMAIL ADDRESS: info@nwpf.org

Date _____

Name of person being referred _____

Mailing Address _____

Phone _____ **Email** _____

Preferred contact method Phone or Email or No Preference (circle one)

May we identify ourselves as Northwest Parkinson's when we contact you? _____

If there's someone else at this number we can speak to, please provide name _____

Do you want to be on our mailing list and receive The Weekly email newsletter? _____

I give permission to my provider to give my name and contact information to NW Parkinson's Foundation and to subsequently contact NW Parkinson's in the future on my behalf. I understand a NW Parkinson's representative will contact me about free support, resource, and educational services that are available to me. I understand that my name and contact information listed above will not be disclosed or shared with any other entity besides NW Parkinson's unless I specifically authorize any subsequent disclosure. I understand that unless I selected yes above, I will not receive mail from NW Parkinson's unless I give permission when contacted. I understand that I can revoke my permission at any time by contacting NW Parkinson's. I give permission to NW Parkinson's to let the provider know whether contact was made with me.

Signature of person being referred _____

TO BE COMPLETED BY REFERRING PROVIDER

The person being referred provided verbal consent instead of signature Yes (circle) Date _____

Provider Name _____ **Organization** _____

Provider Email _____ **(For notice as to whether contact was made)**

Provider signature _____

Reason for referral

- ☐ Individualized Care Consultation (social work services)
- ☐ HOPE Kit (resource packet for newly diagnosed)
- ☐ Support Group/ PD Link Peer to Peer Support Program
- ☐ Carepartner concerns
- ☐ Education
- ☐ Young Onset concerns
- ☐ Other _____

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Questions?

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