WELCOME TO EXPERT BRIEFINGS!

- The program will begin at the top of the hour
- Meeting attendees will be muted
Our Mission

The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience and passion of our global Parkinson's community.

We have everything you need to live better with Parkinson's.

Our Goals

To help our global community live better with Parkinson's, we pursue three goals:

- Improve care for everyone with Parkinson's
- Advance research toward a cure
- Empower and educate our global community
Thank You!

Genentech
A Member of the Roche Group

For Your Convenience

RECORDING
Expert Briefings are recorded and archived on Parkinson.org/ExpertBriefings within one week

SLIDES
Download today’s presentation via link in the chat.
Poll: Getting to Know You

What best describes your connection to Parkinson’s disease (PD)?

• Person with PD
• Spouse/Partner
• Parent has/had PD
• Other family of person with PD
• Healthcare Professional
• Physician/Clinician
• Scientist/Researcher
• Nurse/Nurse Practitioner
• Other

Meet Your Presenters

Annie Killoran, MD, MSc
Clinical Associate Professor Neurology
*University of Iowa Hospitals and Clinics

Lance Wilson, MSS, LSW, C-SWHC,ASW-G
Social Worker & Education and Outreach Coordinator
*Jefferson Health

* Parkinson’s Foundation Center of Excellence
The Parkinson's Journey: Understanding Progression

Annie Killoran, MD
University of Iowa
Parkinson's Foundation Center of Excellence
09/01/2021

Disclosures

NeuroNext funding for ENLITE-PD study

CHDI funding for Enroll-HD study
Learning Objectives

Learn how the stages of Parkinson’s progression is measured
Understand why people with PD have different paths of progression
Know where you fit in the course of Parkinson’s

Hoehn and Yahr (H&Y) scale

PD is neurodegenerative
How do we measure disease progression?
Clinically: symptoms & UPDRS
Hoehn and Yahr (H&Y) 5-point scale commonly used\(^1,2\)

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Hoehn and Yahr (H&Y) stages

Time-line for stages varies
Most people go up one stage every 2 years,
except for stage 2, which is ~ 5 years¹
~1/3rd remain in stage 1 or 2 for up to 10 years²

H&Y stage 3: falls

Stage 3 (falling) is a significant milestone with deterioration in QOL. Of people with PD for 15 years, 80% have recurrent falls. At 18 - 20 years with PD, most are using a wheelchair.

Risk Factors for Falls in PD:
- Being >70 years
- Being diagnosed with PD at an older age
- PD dementia: 3-4 times more likely to have recurrent falls

Reduce falls with physical therapy and walking aids. Dementia drugs (Donepezil & Rivastigmine) may reduce falls.

Non-motor symptoms: RBD

H&Y staging only uses main PD motor features: shaking, slowness, stiffness & stumbling

Non-motor symptoms include disturbances of sleep, mood, cognition and autonomic control

Start in “pre-motor” phase, up to 20 years earlier: constipation, hyposmia, depression & REM sleep behavior disorder (RBD)

~50% of people with PD have RBD (underestimate?)
RBD is associated with faster progression.
Non-motor symptoms: Cognitive issues

Early slowness of thinking gradually increases
Multi-tasking, problem-solving, staying focused & word-finding
Dementia in PD ranges between 24 - 50% ~ 85% at 18 - 20 years with PD or by age 90 years

Over half of people with PD dementia have apathy & depression & ~ 3/4th have hallucinations

Biggest risk factors for PD dementia:
> 70 years of age
Older when PD diagnosed
NOT having a prominent tremor

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<th>Subtype</th>
<th>Tremor-dominant</th>
<th>NON-tremor dominant</th>
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<tr>
<td>1st SYMPTOM</td>
<td>Tremor</td>
<td>Slowness/stiffness</td>
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<tr>
<td>PROGRESSION</td>
<td>Slower</td>
<td>Faster</td>
</tr>
<tr>
<td>IMBALANCE</td>
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<td>More</td>
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<tr>
<td>LIGHTHEADNESS</td>
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<td>COGNITION</td>
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<td>More</td>
</tr>
<tr>
<td>DEPRESSION &amp; APATHY</td>
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<td>More</td>
</tr>
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</table>

Motor subtypes

The pathology is more widespread in non-tremor-dominant PD\(^1\)

Tremor-dominant gradually become non-tremor subtype\(^2\):
Half of patients within the first 5 years with PD\(^3,4\)
Only 11% have tremor at 15 years with PD\(^5\)

Once tremor gone, dementia and balance problems start \(^6\)

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<table>
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<tr>
<td>DYSKINESIA</td>
<td>More</td>
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</tbody>
</table>

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Advanced PD

Aging process interacts with disease process, making it worse. Advanced PD progresses the same in all, regardless of onset age.

Of people with PD for 10 years: 25% will have advanced PD
Of people with PD for 15 years: 50% will have advanced disease.

After PD for 20-years, most people were in nursing homes.
Main predictors for nursing home placement: visual hallucinations, falls & dementia.


Treatment

PD treatment evolves with disease progression
PD medication very effective in early disease.
Then motor complications, which adds complexity to the drug regimen.

Treatment complications

“Wearing off”
First motor complication
Medication benefit short-lived so need more frequent dosing

Dyskinesias
Involuntary wiggling in stage 2 & 3
Can reduce levodopa OR add anti-dyskinesia drug

“Dose failures” & “sudden OFFs”
Occur in advanced PD
Drug has no effect or benefit stops suddenly & unpredictably¹
Rescue medications may help


In advanced disease, levodopa less effective¹-⁵:
20% got ≥30% motor improvement from levodopa
& 50% saw < 15% improvement from levodopa⁶

Medication side effects can limit dosing:
sleepiness⁷
lightheadedness on standing⁹-¹⁰
hallucinations¹¹

The Parkinson’s Journey: Understanding Progression

Lance M. Wilson, MSS, LSW, C-SWHC, ASW-G
Social Worker, Education & Outreach Coordinator

Jefferson Health Comprehensive Parkinson’s Disease and Movement Disorder Center at the Vickie & Jack Farber Institute for Neuroscience
Parkinson’s Foundation Center of Excellence

Lancet 2015; 386 (9996): 896–912

Overview

• The Practical
• Measurement
• The Hard Conversations
• Self-Work & Maintenance
• Resources & Benefits

The Practical

• Maintenance PT/OT/SLP & Exercise Programs
• Durable Medical Equipment (DME)
• Home Health
• Medication
• Neurology Follow-Up
The Multidisciplinary Team

- How can we keep tabs?
  - Development of a Baseline – Never too late
    » Movement Disorder Specialist (MDS)
    » PT/OT/SLP
    » RN/CRNP/PA-C
    » Neuropsychology
    » Social Worker (SW) / Mental Health Provider

  “Care Map”

The Hard Conversations

- MDS
  - Addressing symptoms
    » Misperceptions / Hallucinations
    » Intimacy
    » Etc.
  - “White Coat Syndrome”

- Letting People “In” / Disclosure

- Requiring More Assistance
  - Long-Term Planning (Aging in Place / Facilities)
  - Care Partners - Do I help?”
Self-Work & Maintenance

• How you feel is valid!

• Leaning In vs The Spiral

• What do you need?
  • Attainable Goals

This goes for the care partner as well…

Self-Work & Maintenance (continued)

• Be Mindful of Emotions
  • Projection

• Therapy
  • Psychotherapy or “Talk Therapy”
  • Medication / Psychiatry
Resources & Benefits

- Palliative Care Consult
  - Outpt
  - In-Home
- Local Office for Aging/Disability
- Elder Care Attorney – Financial Planning
- CMS – Medicare.gov
- Social Workers
  - Institution
  - Insurance

Overall…

- Your OUTLOOK and your ENGAGEMENT in your WELLNESS will shape the trajectory along the PD continuum
- Be Kind to Yourself
**Expert Briefings 2021-2022**

**Wednesday, September 1**

The Parkinson’s Journey: Understanding Progression
Ann K. Reagan, MD, Msc
Lance Wilson, BSS, LSW, GSWHC, ASW-G

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**Wednesday, October 6**

PD & Medication: What’s New
Vanessa Hinson, MD, PhD

**Wednesday, December 1**

The Skinny on Skin and Bone Health in Parkinson’s
Kenneth W. Lyles, MD
Nicki Niemann, MD

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**Wednesday, February 2**

Sights, Sounds and Parkinson’s
Ali G. Hamedani, MD, MHS

**Wednesday, March 2**

Conversations About Complementary Therapies and PD
Natalie Diaz, MD

**Wednesday, April 6**

Can We Put the Brakes on PD Progression?
Joash Lazarus, MD

Register at Parkinson.org/ExpertBriefings

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**Resources and Support**

**Aware in Care**
The Aware in Care Parkinson’s hospital kit protects, prepares and empowers people with Parkinson’s before, during and after a hospital visit.
Parkinson.org/AwareInCare

**PD Library**
Extensive collection of books, fact sheets, videos, podcasts and more.
Parkinson.org/PDLibrary

**PD GENERation**
National initiative that offers genetic testing for relevant Parkinson’s-related genes and counseling at no cost.
Parkinson.org/PDGeneration

**Podcast: Substantial Matters**
Parkinson’s experts highlight treatments and techniques to help you live well now and explore current research to bring you a better tomorrow.
Parkinson.org/Podcast

**PD Health @ Home**
Weekly events designed for you. Engage and join us virtually for, Mindfulness Mondays, Wellness Wednesdays and Fitness Fridays.
Parkinson.org/PDHealth

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