Here. Until Parkinson's Isn't.

THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

- Launched in **2000** by actor Michael J. Fox

- Global strategic funder and facilitator: more than **$1 billion** deployed to Parkinson's disease research and drug development

- Vision seeks **a world without Parkinson's disease**

- Mission execution through a **strategic research vision** centered on *enabling* advances in disease *definition*, *measurement* and *treatment* across the Parkinson's disease progressive journey

- Accelerating cures by **connecting community**: people with Parkinson's, care providers, researchers, industry, regulators, payers, policy-makers, strategic partners and other visionary philanthropists

The Challenge of Parkinson's Disease

Progressive and heterogeneous disease course requires targeting variety of patient needs and underlying biology
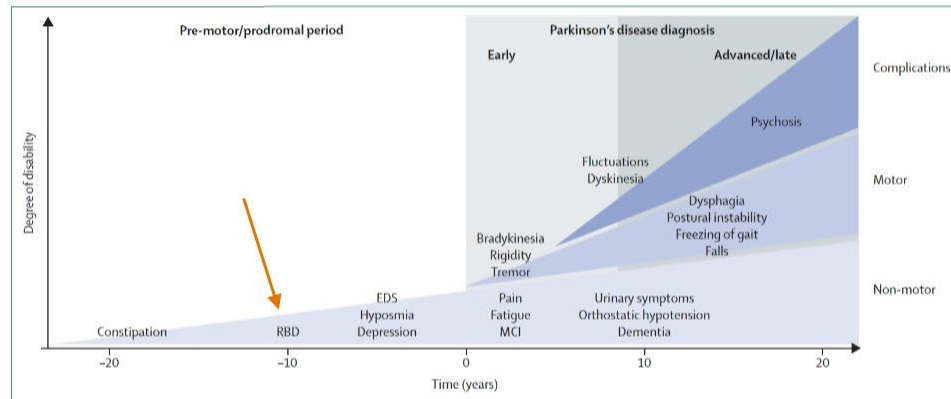
Key Symptoms
- Motor and non-motor features
- Disease 'subtypes' (e.g., gait vs tremor dominant)

Pathology
- Loss of dopamine cells in substantia nigra (among other regions)
- Presence of intraneuronal 'Lewy body' protein (alpha-synuclein) pathology in many but not all cases (other pathology, too)

Approved Treatments
- Dopamine replacement/restoration
- Neuromodulation (stimulation or ablation)
- Some non-motor treatments (often not PD-specific)
- Progressive treatment complications
- *No disease-slowing therapies*

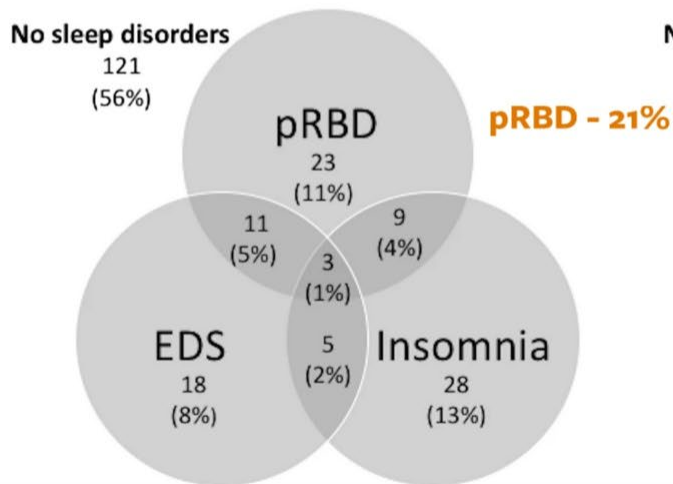image: Kalia and Lang, *The Lancet*, 2015

Sleep disturbances are common in Parkinson's disease

Progression over first five years from diagnosis reflects growing impact on quality of life
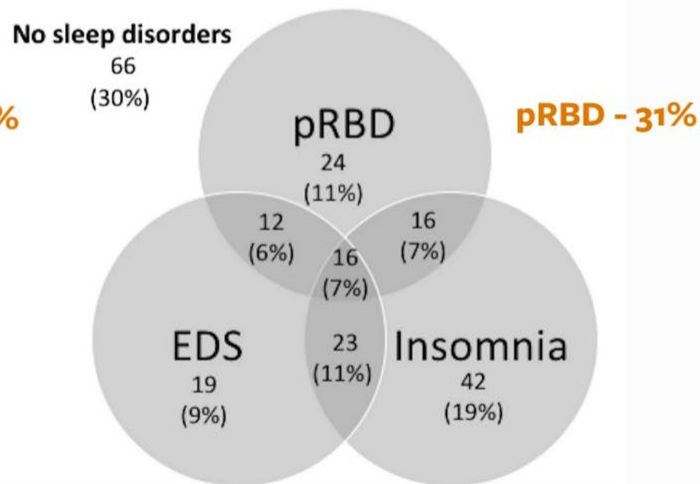
PD: Spectrum of sleep disturbances at baseline

A   **44% with sleep disorders**

No sleep disorders
121
(56%)

pRBD
23
(11%)

pRBD – 21%

11
(5%)

9
(4%)

3
(1%)

EDS
18
(8%)

5
(2%)

Insomnia
28
(13%)

PD: Spectrum of sleep disturbances after 5 years

B   **70% with sleep disorders**

No sleep disorders
66
(30%)

pRBD
24
(11%)

pRBD – 31%

12
(6%)

16
(7%)

16
(7%)

EDS
19
(9%)

23
(11%)

Insomnia
42
(19%)

Venn diagram showing the spectrum of sleep disturbances in the Parkinson's disease (PD) group at baseline (**a**) and 5 years (**b**)

Data from the Parkinson's Progression Markers Initiative (Xu et al., J Neurol 2021)

Workshop Perspectives

How can we best approach sleep as contributor and/or outcome of diseases like Parkinson's disease?

- Light as environmental 'toxin' influencing brain health - public awareness and behavior adjustment hard (think exercise...) so may need other solutions

- Not all sleep the same - need for a precision medicine approach (or more precise language) to addressing sleep in context of specific CNS disorders - potential for multi-modal clinical/biomarker subtyping?

- Sleep measurement is getting easier (applied technologies) but also messier (inconsistent validation, proprietary algorithms, etc.) - data standards (FAIR?) and more open source collaboration would be helpful

- Chicken/egg problem - does sleep trigger/promote neurodegeneration or vice versa (or something more in between)? More data (in people) needed