Data collection, curation and sharing is critical to accelerating progress.
ACROSS DISEASES, LACK OF DATA ON CAUSES AND TRAJECTORY LIMITS PROGRESS

PRESYMPTOMATIC
- Identify at risk
- Prevent

EARLY SYMPTOMATIC
- Improve diagnosis
- Slow, stop, protect

LATE SYMPTOMATIC
- Manage disease
- Restore, repair, replace
TECHNOLOGY IS ALLOWING UNPRECEDENTED SCOPE AND DEPTH OF DATA COLLECTION

- Epidemiology
- Genetics
- Patient-reported Data
- Diagnosis and Clinical Symptoms
- Imaging
- Response to Available Treatments
MJFF-LED STUDIES DEFINING PARKINSON’S BIOLOGICALLY AND FUNCTIONALLY
PPMI HAS ENROLLED MORE THAN 1,000 PARTICIPANTS AT 33 INTERNATIONAL SITES

<table>
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<th>24 mo.</th>
<th>36 mo.</th>
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Data from studies using PPMI data/samples is entered back into the PPMI database.
PARTNERSHIP AIMS TO INTEGRATE DATA ON PATIENT BENEFIT/RISK PERSPECTIVE IN TRIALS
SURVEY CAPTURED PATIENT POSITION ON EARLY-STAGE SURGICAL PROCEDURE

Patient Perspectives on Deep Brain Stimulation Clinical Research in Early Stage Parkinson’s Disease.

Heusinkveld L1,2, Hacker M1, Turchan M1, Bollig M1, Tamargo C1, Fisher W1, McLaughlin L3, Martig A3, Charles D1.

Abstract
The FDA approved a multicenter, double-blind, Phase III, pivotal trial testing deep brain stimulation in 280 people with very early stage Parkinson’s disease (PD; IDE#G050016). In partnership with The Michael J. Fox Foundation for Parkinson’s Research, we conducted a survey to investigate motivating factors, barriers, and gender differences for participation in a trial testing DBS in early PD. The majority of survey respondents (72%) indicated they would consider learning more about participating. Men and women with early PD are likely to consider enrolling in trials of invasive therapies that may slow symptom progression and help future patients.
HOW DO WE OPTIMIZE USE OF THIS DATA?

- Engage programmatic partners
- Build infrastructure for access to curated data
- Encourage analysis with data challenges
PPMI’S 19 INDUSTRY PARTNERS OFFER FINANCIAL AND INTELLECTUAL SUPPORT
PPMI DATA, AVAILABLE IN REAL-TIME, HAS BEEN DOWNLOADED >800,000 TIMES
DATA CHALLENGES ATTRACT EXPERT ANALYSTS TO GLEAN NOVEL INSIGHTS

2016 PPMI Data Challenge

- Posed two Parkinson’s research-relevant questions
- Offered two $25,000 prizes (partnership with GE Healthcare)
- Marketed to data scientists
- Offered Parkinson’s expert collaborators
- Chose winners from 38 entries (Researchers at UCSF, Weill Cornell)
LRRK2 Antibody Comparison Effort

MJFF offered 10 LRRK2 antibodies for crowd-source testing

More than 100 returned methods and data reports

Well-characterized antibodies now standard for the field

doi:10.1042/BJ20121742