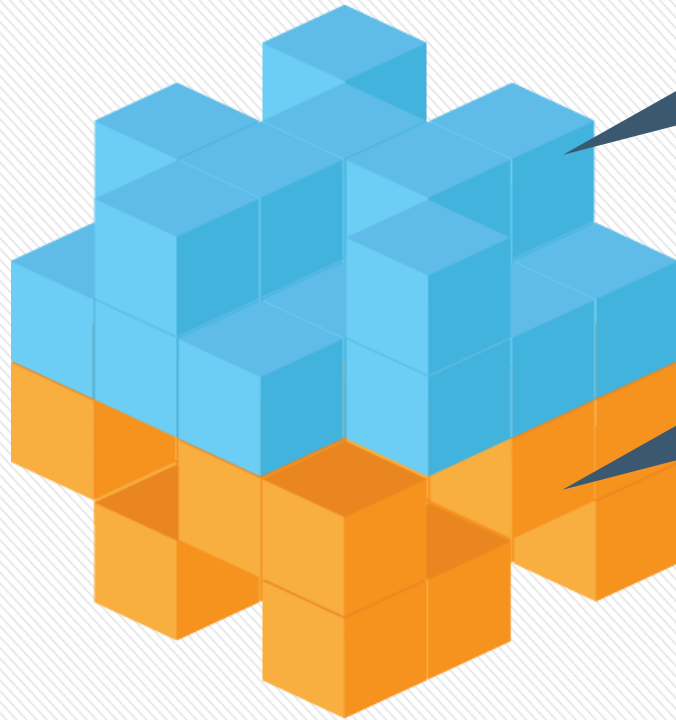




PARTNERING AROUND DATA TO ACCELERATE RESEARCH

Todd Sherer, PhD
The Michael J. Fox Foundation

PROGRESS REQUIRES FUNDING AND FIELD-WIDE COORDINATION



Driving Therapeutics

- » Funding discovery work to identify novel targets
- » De-risking early-stage projects

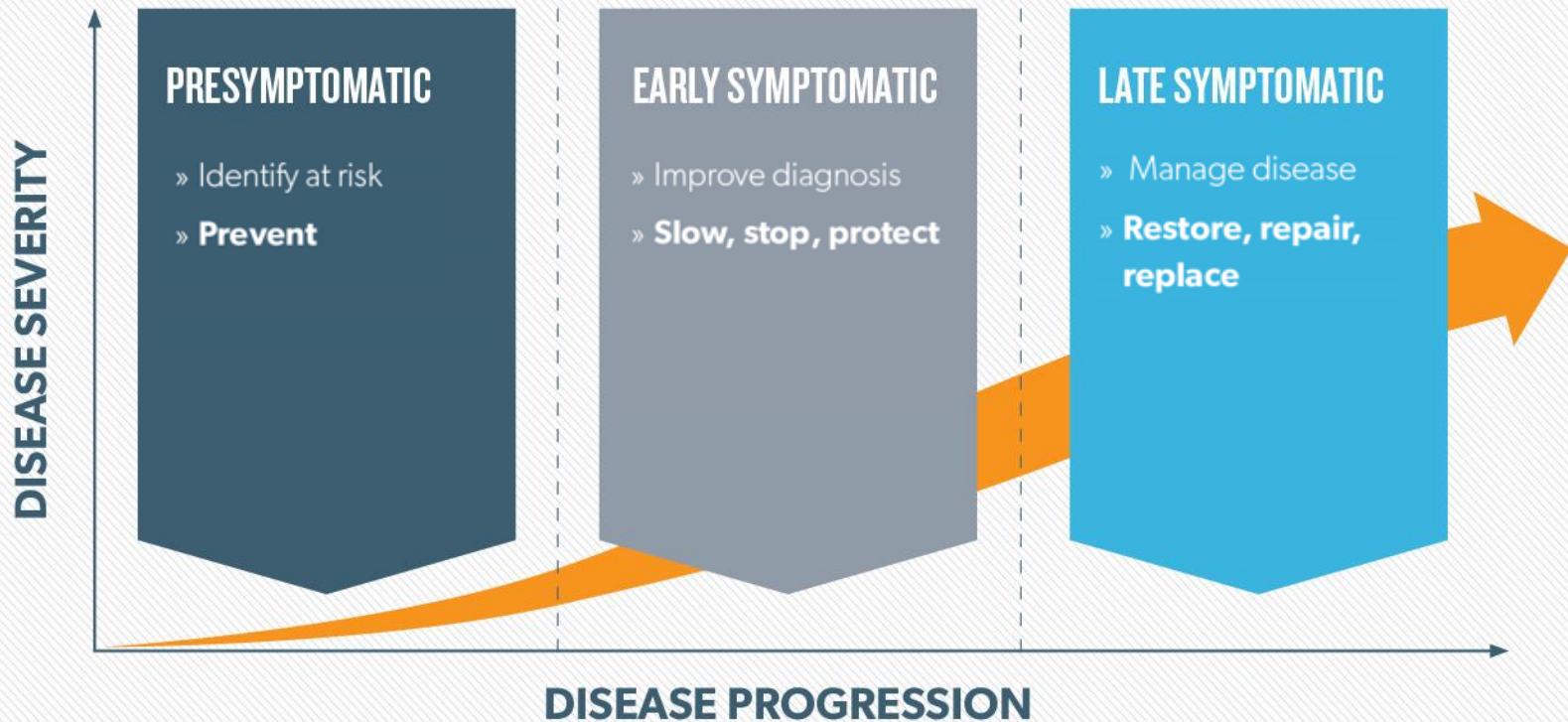
Accelerating Progress

- » Developing critical, accessible research tools
- » Validating biological measures of disease
- » Engaging the patient and supporter communities

Data collection, curation and sharing is critical to accelerating progress.



ACROSS DISEASES, LACK OF DATA ON CAUSES AND TRAJECTORY LIMITS PROGRESS



TECHNOLOGY IS ALLOWING UNPRECEDENTED SCOPE AND DEPTH OF DATA COLLECTION



Epidemiology



Genetics



Patient-reported Data



Diagnosis and Clinical Symptoms

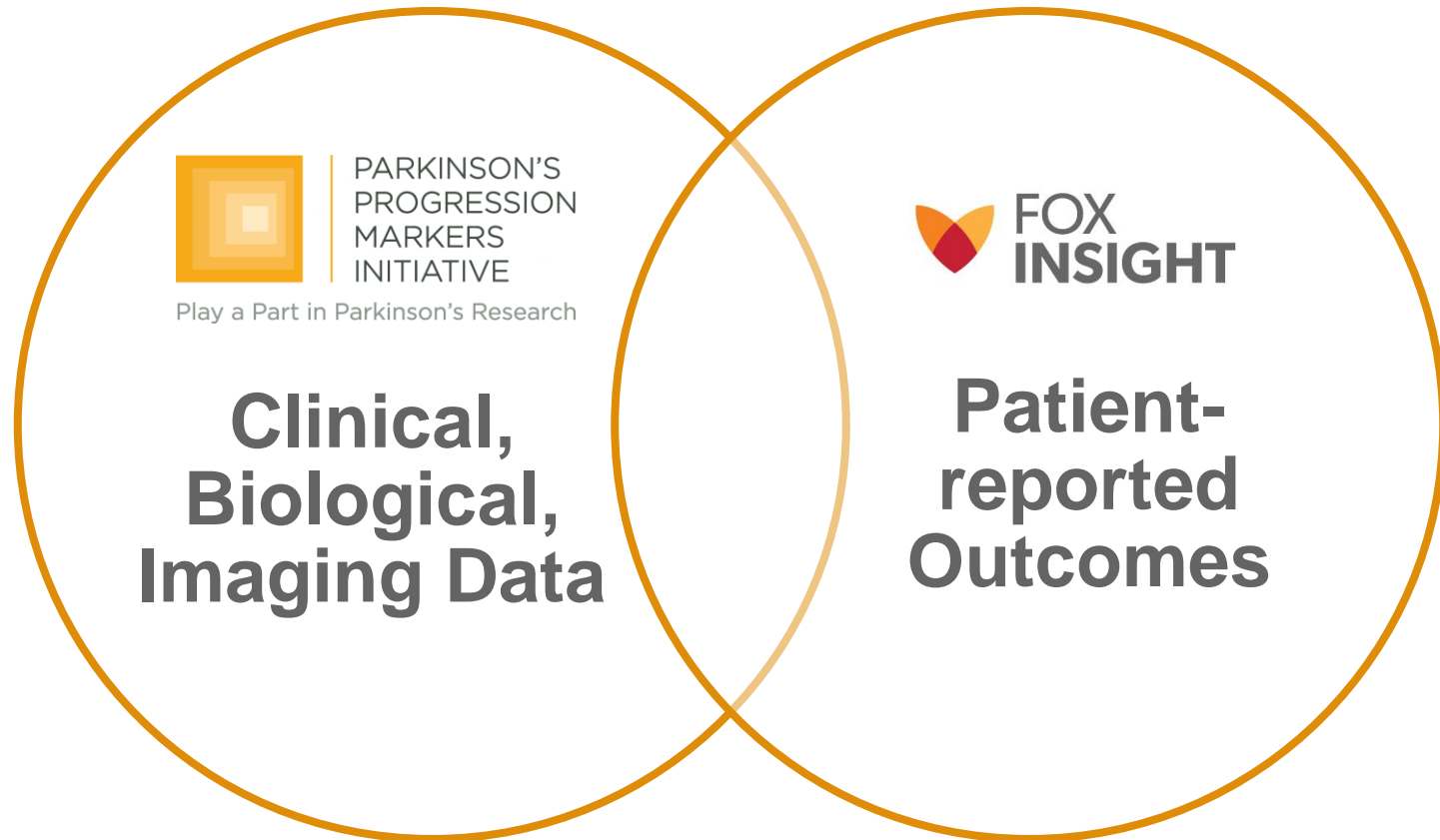


Imaging



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

BIOSAMPLES FROM DE NOVO PARKINSON'S PPMI COHORT

Sample/Scan	Base line	3 mo.	6 mo.	12 mo.	24 mo.	36 mo.	48 mo.	60 mo.
CSF	582	5	390	416	341	307	207	78
DNA	47	4	2		59	208	227	97
RNA	714	530	369	436	557	582	376	118
Plasma	421	387	280	363	359	360	267	109
Serum	417	359	279	363	355	356	264	109
Urine	417	2	284	363	362	356	267	110
Whole Blood	334	338	251	331	330	343	266	109
MRI	432	2	1	162	160		114	1
PET	1			20	20		6	
SPECT		31	1	362	357	5	266	5

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



**Massachusetts
Institute of
Technology**



SURVEY CAPTURED PATIENT POSITION ON EARLY-STAGE SURGICAL PROCEDURE

[J Parkinsons Dis](#). 2016 Nov 30. [Epub ahead of print]

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

[Heusinkveld L](#)^{1,2}, [Hacker M](#)¹, [Turchan M](#)¹, [Bollig M](#)¹, [Tamargo C](#)¹, [Fisher W](#)¹, [McLaughlin L](#)³, [Martig A](#)³, [Charles D](#)¹.

⊕ Author information

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

abbvie



Bristol-Myers Squibb

COVANCE



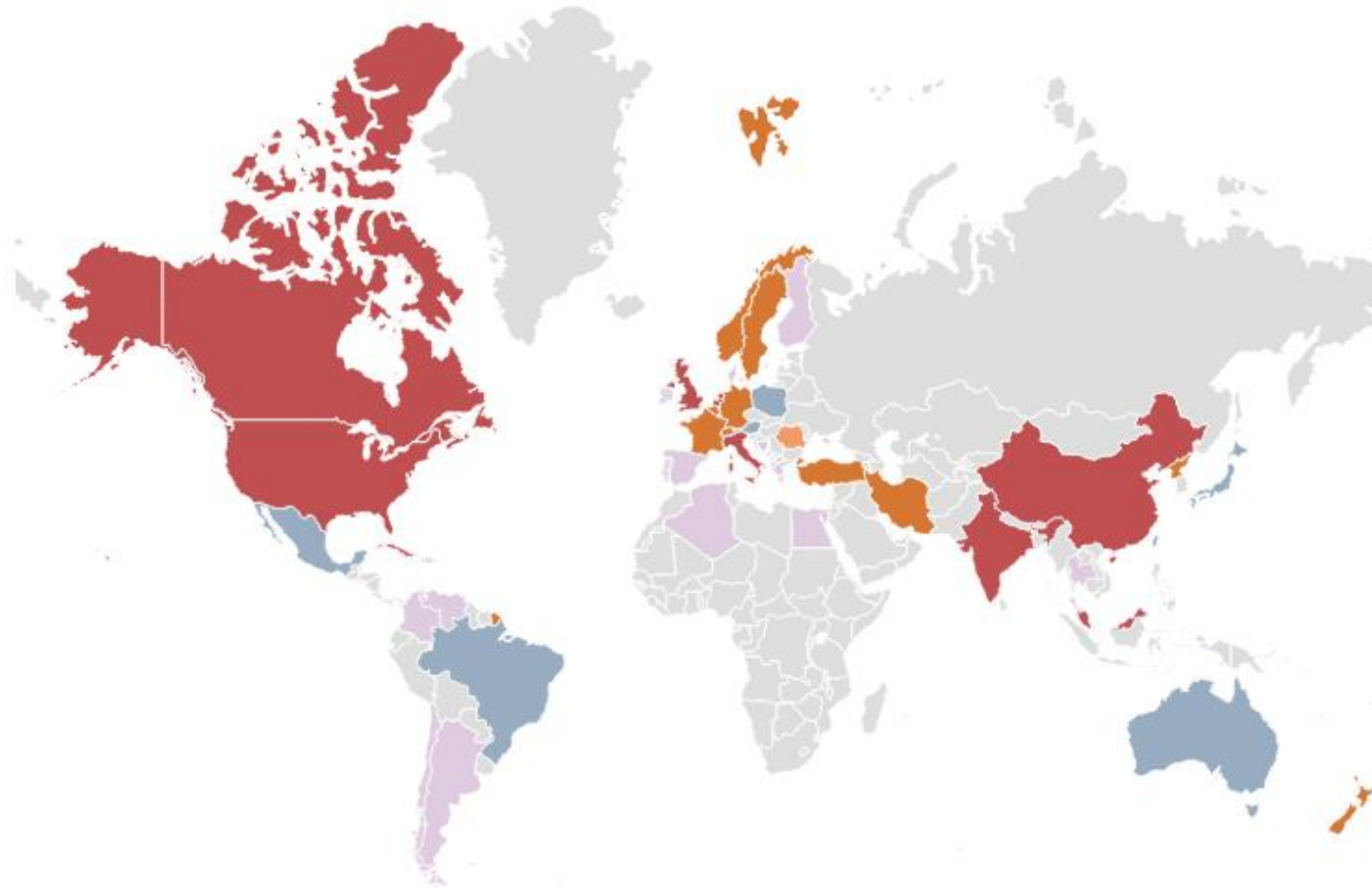
Genentech
A Member of the Roche Group



SANOFI GENZYME



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)



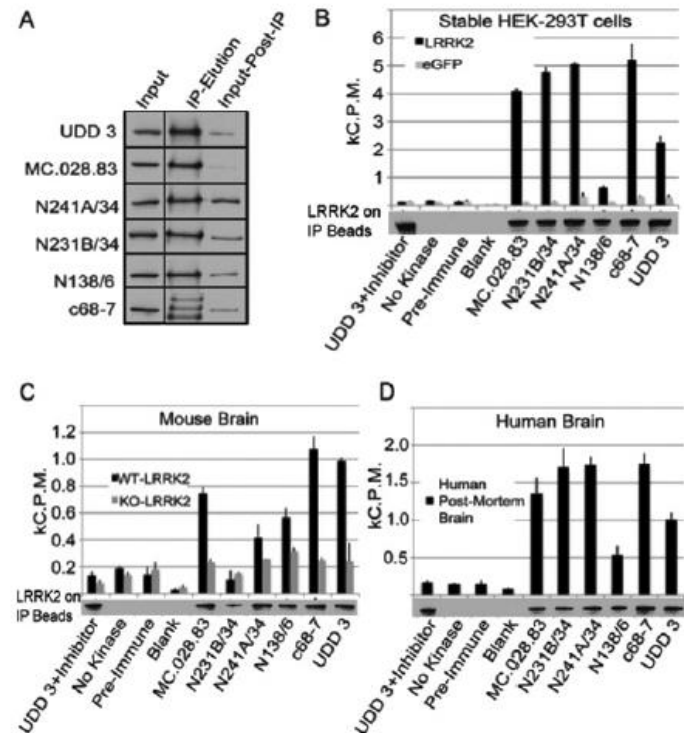
PARTNERING WITH THE BROAD RESEARCH COMMUNITY CAN HELP BUILD DATA

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



Biochem. J. (2013) 453, 101–113
doi:10.1042/BJ20121742





www.michaeljfox.org