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**PPMI 2018 ANNUAL  
INVESTIGATORS MEETING May 2-3**

# NAVIGATING THE PPMI DATABASE

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# OUTLINE

1. Navigating the LONI website
    - a. Requesting data access
    - b. Downloading the data
  
  2. Structure of the data
    - a. Grouping of data tables
    - b. Documents to answer common data questions
  
  3. Data Review
    - a. Finding enrolled subjects
    - b. ST visits
    - c. MDS-UPDRS data
  
  4. Data Example
    - a. Examine longitudinal change in MDS-UPDRS Part III “ON” and “OFF” scores at annual visits over time
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# NAVIGATING THE LONI WEBSITE

## 1. How to request data access

### a. Website options

- i. Go to [ida.loni.usc.edu](http://ida.loni.usc.edu) and click on “APPLY” on the PPMI button
- ii. Go to [www.loni.usc.edu](http://www.loni.usc.edu) and click on “PPMI” on the right sidebar
- iii. Go directly to [www.ppmi-info.org](http://www.ppmi-info.org)

### b. Click on “Download Data” on the right sidebar

### c. Click on “Apply for Data Access” and fill out the request form

### d. After your request is approved, you will receive an email with a link to create your password and finish setting up your account on LONI



# REQUESTING DATA ACCESS

Parkinson's Progression Markers Initiative

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Study Design

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## OUR MISSION

The mission of PPMI is to identify one or more biomarkers of Parkinson's disease progression. The discovery of a biomarker is a critical step in the development of new and better treatments for PD. This study is being sponsored by **The Michael J. Fox Foundation for Parkinson's Research.**

## A LANDMARK STUDY OF PARKINSON'S DISEASE

The Parkinson's Progression Markers Initiative (PPMI) is a landmark observational clinical study to comprehensively evaluate **cohorts of significant interest** using advanced imaging, biologic sampling and clinical and behavioral assessments to identify biomarkers of Parkinson's disease progression.

PPMI is taking place at clinical sites in the United States, Europe, Israel, and Australia. Data and samples acquired from study participants will enable the development of a comprehensive Parkinson's **database and biorepository**, which is currently available to the scientific community to conduct field-changing research.



PARKINSON'S PROGRESSION MARKERS INITIATIVE

# REQUESTING DATA ACCESS

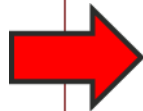
The screenshot shows the top navigation bar of the Parkinson's Progression Markers Initiative website. It features a black header with the text "Parkinson's Progression Markers Initiative". Below this is a light orange banner with a square logo on the left and the text "PARKINSON'S PROGRESSION MARKERS INITIATIVE" and "Play a Part in Parkinson's Research". A grey navigation bar contains links: "About PPMI", "Study Design", "Access Data & Specimens" (highlighted), "Publications & Presentations", and "PPMI News". A bottom orange navigation bar contains links: "Request Specimens", "Request Cell Lines", "Download Data" (highlighted), "Ongoing Analysis", "Data & Specimens FAQ", and "Complete".

## DOWNLOAD DATA

Through this Web site, qualified researchers may obtain access to all clinical, imaging and biomarker data collected in PPMI. This includes raw and processed MRI and SPECT images. All data are de-identified to protect patient privacy.

### New Users Apply Now:

Investigators seeking access to PPMI data must submit an online application, which requires signing the **Data Use Agreement** and compliance with the study **Publications Policy**. Applications for data access are reviewed by the Data and Publications Committee within one week of receipt.



APPLY FOR  
DATA ACCESS

### Registered Users:

Investigators who have been granted access to PPMI data can enter their email and password below.

Email:

Password:

Forgot your login and password? [Click here.](#)

LOGIN



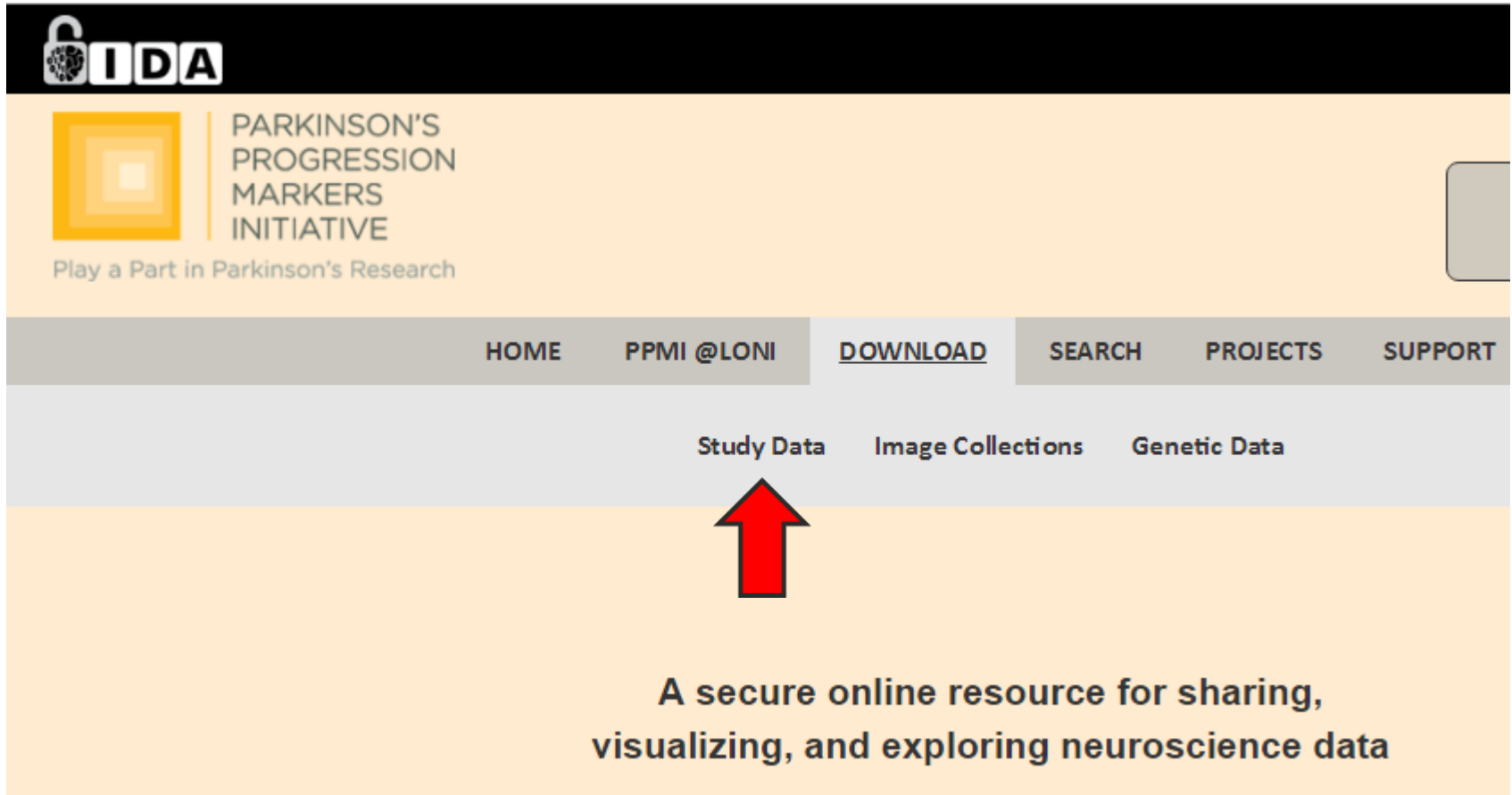
# NAVIGATING THE LONI WEBSITE

## 1. How to download the clinical data

- a. Login to LONI and click on the “Download” tab at the top, then click on “Study Data”
- b. To see all available data files and documents, click on “ALL” at the bottom of the left sidebar
- c. Check the boxes next to specific files you want to download, or check the 2 “Select ALL” boxes at the top to download everything
- d. Click on the “Download>>” button at the top right
- e. Multiple files will be downloaded in a .zip file



# DOWNLOADING THE PPMI DATA



The screenshot shows the top navigation bar of the PPMI website. The logo 'IDA' is in the top left. Below it is the PPMI logo and the text 'PARKINSON'S PROGRESSION MARKERS INITIATIVE' and 'Play a Part in Parkinson's Research'. The navigation bar includes 'HOME', 'PPMI @LONI', 'DOWNLOAD', 'SEARCH', 'PROJECTS', and 'SUPPORT'. Under 'DOWNLOAD', there are sub-links for 'Study Data', 'Image Collections', and 'Genetic Data'. A red arrow points to 'Study Data'. Below the navigation bar is a large orange box with the text: 'A secure online resource for sharing, visualizing, and exploring neuroscience data'.





# DOWNLOADING THE PPMI DATA



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## Download Study Data

- ▶ Study Docs
- ▶ Subject Characteristics
- ▶ Biospecimen
- ▶ Enrollment
- ▶ Imaging
- ▶ Medical History
- ▶ Motor Assessments
- ▶ Non-motor Assessments

[ALL](#)

- Select ALL tabular data (csv format)**
- Select ALL documents and zip files [38.0 MB]**
- Study Docs**
  - ALL Data & Databases
    - [Code List](#)
    - [Data Acquisition and Usage](#)
    - [Data Dictionary](#)
    - [Derived Variable Definitions and Score Calculations](#)
    - [Page Descriptions](#)

Version: 2014-06-09



# DATA STRUCTURE

1. Currently there are 96 data tables (.csv files) comprising both clinical and lab data
2. Clinical Data Tables have a file name and a “Page Name” (variable: PAG\_NAME)
  - a. Data Dictionary refers to tables by their Page Name
3. Lab Data Tables
  - a. Includes DaTSCAN SBR results, CSF biospecimen results, blood chemistry and hematology, etc.
  - b. Lab data often structured differently than clinical data
    - i. Subjects may have multiple observations for each visit because of multiple types of tests done



# USEFUL FILES TO ANSWER COMMON DATA QUESTIONS

1. Data Dictionary (CSV file) – lists all variables in each data table with a brief description
2. Code List (CSV file) – lists every categorical variable with each possible response (CODE) and what the response means (DECODE)
  - a. CODE = 1; DECODE = “Yes”
3. Case Report Forms (PDF file)
  - a. “PPMI-CRF-All-in-One-AM13”
4. Derived Variable Definitions and Score Calculations (CSV file) – explains how to calculate total scores, find enrolled subjects, etc.



# DATA REVIEW: FINDING ENROLLED SUBJECTS

1. Need two tables: SCREEN (Screening/Demographics) and RANDOM (Randomization table)
2. Enrolled subjects **must** appear in both tables
3. Enrolled subjects **must** also have a non-missing enrollment date (ENROLLDT from the RANDOM table)



# DATA REVIEW: ST VISITS

1. These are visits where symptomatic therapy is begun. These do not necessarily align with planned study visits, but sometimes do take the place of a regular study visit
2. The data file ST\_CATALOG contains a list of all subjects who have had an ST visit
  - a. If the ST visit replaced a regular visit, the visit will be noted in the variable “STRPLCVS”
  - b. If the ST visit did NOT replace a regular study visit, the variable “STRPLCVS” will be blank

	PATNO	STRPLCVS	STVIS
1	3400	V02	1
2	3403	V02	1
3	3406	V02	1
4	3502	V02	1
5	3056	V02	1
6	3409	V03	1
7	3252	V03	1
8	3251	V02	1
9	3451	V02	1
10	3500	V03	1
11	3504	V02	1
12	3800	V02	1
13	3557	V02	1
14	3558	V01	1
15	3601	V02	1



# DATA REVIEW: ST VISITS, CONT.

1. There are special circumstances surrounding ST visits that replaced either Visit 01 (3 Months) or Visit 03 (9 Months):
  - a. If an ST visit replaced Visit 01 or Visit 03, then per protocol the subject was supposed to skip Visit 02 (6 Months) or Visit 04 (12 Months), respectively.
  - b. If Visit 02 or Visit 04 are missing because of an ST visit that replaced Visit 01 or Visit 03, that ST visit is grouped with Visit 02 or Visit 04.
  - c. The schedule of activities for an ST visits more closely resemble those of Visits 02 and 04 than they do Visits 01 and 03.



# DATA REVIEW: MDS-UPDRS DATA

1. The MDS-UPDRS is made up of 4 parts that are collected using 6 CRFs
2. These are stored in 5 separate data files (PAG\_NAMES in parentheses):
  - a. Part 1
    - i. MDS\_UPDRS\_Part\_I.csv (NUPDRS1)
    - ii. MDS\_UPDRS\_Part\_I\_Patient\_Questionnaire.csv (NUPDRS1P)
  - b. Part 2: MDS\_UPDRS\_Part\_II\_Patient\_Questionnaire.csv (NUPDRS2P)
  - c. Part 3: MDS\_UPDRS\_Part\_III\_Post\_Dose\_.csv (NUPDRS3 / NUPDRS3A)
    - i. NOTE: Both CRFs are in a single data file, so there can be up to two records per visit
  - d. Part 4: MDS\_UPDRS\_Part\_IV.csv (NUPDRS4)



# DATA REVIEW: MDS-UPDRS “ON” AND “OFF” SCORES

1. At the annual visits only, subjects taking Levodopa/Dopamine Agonists complete a defined “ON” and defined “OFF” medication score
  - a. Subjects are asked to withhold their medication prior to the visit for at least 6 hours, then the Part III (Motor) of the MDS-UPDRS is assessed during the visit for a defined “OFF” medication score
  - b. The subject takes standard dose of medication. Approximately 1 hour after the ‘in clinic’ dose, Part III (Motor) of the MDS-UPDRS is assessed again for a defined “ON” medication score





# DATA REVIEW: MDS-UPDRS “ON” AND “OFF” SCORES, CONT.

1. The following variables distinguish between ON and OFF assessments in the NUPDRS3 data:
    - a. ON\_OFF\_DOSE – whether assessment is defined as ON or OFF (1 = OFF; 2 = ON)
    - b. ANNUAL\_TIME\_BTW\_DOSE\_EXAM – number of hours between most recent dosing and Part III exam
    - c. PD\_MED\_USE – subject’s class of PD medication (corresponds to Use of PD Medication CRF)
      - 0 = Unmedicated for PD
      - 1 = Levodopa
      - 2 = Dopamine Agonist
      - 3 = Other PD Med
      - 4 = Levodopa + Other
      - 5 = Levodopa + Dopamine Agonist
      - 6 = Dopamine Agonist + Other
      - 7 = Levodopa + Dopamine Agonist + Other
  
  2. Note: ON/OFF definitions do NOT apply to subjects with PD\_MED\_USE coded as ‘0’ or ‘3’, so ON\_OFF\_DOSE and ANNUAL\_TIME\_BTW\_DOSE\_EXAM are missing values
- 



# DATA EXAMPLE: MDS-UPDRS “ON” AND “OFF” SCORES OVER TIME

1. Goal: Examine the longitudinal change in MDS-UPDRS Part III “OFF” and “ON” scores at annual visits for enrolled PD subjects while accounting for ST visits
2. What we will need:
  - a. Find all enrolled subjects and select PD subjects (APPRDX = 1)
  - b. Take the NUPDRS3 table and merge it with the ST\_CATALOG table based on the subject ID (PATNO) variable
  - c. Merge the enrolled PD subjects with their records in the NUPDRS3 table
  - d. Examine the MDS-UPDRS “OFF” and “ON” scores over time



# DATA EXAMPLE, CONT.

1. Get the ST\_CATALOG table

VIEWTABLE: Ppmi.Stcat			
	PATNO	STRPLCVS	STVIS
1	3400	V02	1
2	3403	V02	1
3	3406	V02	1
4	3502	V02	1
5	3056	V02	1
6	3409	V03	1
7	3252	V03	1
8	3251	V02	1
9	3451	V02	1
10	3500	V03	1
11	3504	V02	1
12	3800	V02	1
13	3557	V02	1
14	3558	V01	1
15	3601	V02	1

2. Merge the ST\_CATALOG and the NUPDRS3 tables and calculate the NEW\_EVENT\_ID coding

VIEWTABLE: Work.Example_st				
	PATNO	STRPLCVS	EVENT_ID	NEW_EVENT_ID
299	3062	V06	BL	BL
300	3062	V06	ST	V06
301	3062	V06	V04	V04
302	3062	V06	V08	V08
303	3062	V06	V08	V08
304	3062	V06	V10	V10
305	3062	V06	V12	V12
306	3062	V06	V12	V12

VIEWTABLE: Work.Example_st				
	PATNO	STRPLCVS	EVENT_ID	NEW_EVENT_ID
2342	3516	V03	BL	BL
2343	3516	V03	ST	V04
2344	3516	V03	V06	V06
2345	3516	V03	V08	V08
2346	3516	V03	V10	V10



# DATA EXAMPLE, CONT.

3. Use the *PPMI Derived Variable Definitions and Score Calculations* document to calculate Part III score

4. Merge with enrolled PD Subjects and keep the annual visits. We now have the ON and OFF MDS-UPDRS Part III scores over time.



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Motor Assessments		
MDS-UPDRS Part I	NP1COG, NP1HALL, NP1DPRS, NP1ANXS, NP1APAT, NP1DDS, NP1SLPN, NP1SLPD, NP1PAIN, NP1URIN, NP1CNST, NP1LTHD, NP1FATG  Part I Score = sum of these 13 variables	NUPDRS1, NUPDRS1P
MDS-UPDRS Part II	NP2SPCH, NP2SALV, NP2SWAL, NP2EAT, NP2DRES, NP2HYGN, NP2HWRT, NP2HOBB, NP2TURN, NP2TRMR, NP2RISE, NP2WALK, NP2FREZ  Part II Score = sum of these 13 variables	NUPDRS2P
MDS-UPDRS Part III	NP3SPCH, NP3FACXP, NP3RIGN, NP3RIGRU, NP3RIGLU, NP3RIGRL, NP3RIGLL, NP3FTAPR, NP3FTAPL, NP3HMOVR, NP3HMOVL, NP3PRSPL, NP3PRSPL, NP3TTAPR, NP3TTAPL, NP3LGAGR, NP3LGAGL, NP3RISNG, NP3GAIT, NP3FRZGT, NP3PSTBL, NP3POSTR, NP3BRADY, NP3PTRMR, NP3PTRML, NP3KTRMR, NP3KTRML, NP3RTARU, NP3RTALU, NP3RTARL, NP3RTALL, NP3RTALJ, NP3RTCON  Part III Score = sum of these 33 variables	NUPDRS3

VIEWTABLE: Work.Example					
	PATNO	NEW_EVENT_ID	ON_OFF_DOSE	PD_MED_USE	updrs3_score
76	3001	BL		0	12
77	3001	V04		0	20
78	3001	V06		3	39
79	3001	V08	2	6	34
80	3001	V10	1	4	39
81	3001	V10	2	4	35
82	3001	V12	1	4	34
83	3001	V12	2	4	26
84	3002	BL		0	17
85	3002	V02		0	21
86	3002	V04	1	1	27
87	3002	V04	2	1	23
88	3002	V06	2	1	22
89	3002	V08	1	1	31
90	3002	V08	2	1	24
91	3002	V10	2	1	29
92	3002	V12	2	1	30



# ADDITIONAL RESOURCES

1. If you have additional questions about the data, try the following links:

<http://www.ppmi-info.org/access-data-specimens/data-faq/>

<http://www.ppmi-info.org/study-design/statistician-forum/>



# ACKNOWLEDGEMENTS

Thanks to Dr. Eric Foster and Dr. Tanya Simuni for creating a few of these slides.

