

INSTRUCTIONS FOR ACCESSING CURATED PPMI DATA

BACKGROUND

Thank you for your interest in curated Parkinson's Progression Markers Initiative (PPMI) data! The Michael J. Fox Foundation for Parkinson's Research (MJFF) is extremely excited to make curated PPMI data available for download and in tranSMART, a knowledge management platform, through the MJFF data access center. PPMI is an ongoing, longitudinal observational study of idiopathic Parkinson's disease (PD) patients, age- and gender-matched controls, and affected and unaffected individuals with clinical risk factors (REM Sleep Behavior Disorder or hyposmia) or genetic risk factors (mutations in LRRK2, GBA, or SNCA) for PD.

The **PPMI database** is open access. Raw data from recently occurring clinical visits are added to the database weekly; results from analyses of PPMI biospecimen are added to the PPMI database as analyses are completed. Curated data is not as current as the raw data (i.e., not available in real-time) because data curation is a time-intensive process. There may be discrepancies between the curated data in the MJFF data access center and the raw data in the PPMI database. The curated data currently available in the MJFF data access center was pulled from the PPMI database on *August 19, 2016*.

MJFF is interested in researcher feedback on the utility of curated PPMI data. Please email resources@michaeljfox.org for additional information or opportunities to contribute funding to accelerate the curation and harmonization of updated data cuts.

REGISTERING FOR ACCESS TO MJFF DATA ACCESS CENTER

If this is your first time attempting to access data through the MJFF data access center, you'll first need to register for an account.

1. To register for access to the MJFF data access center, first click here: <https://neuroshare.michaeljfox.org/>.
2. After clicking the link above, click **create account**, enter the requested account information, and click **register**.
3. After creating an account, you will receive an automated email with a link to confirm your registration. After clicking the link in this automated email, you will receive one final email confirming that your account is now active.

Please note: You will only need to register for access to the MJFF data access center once. In addition, creating an account will allow you to see if additional datasets become available through the data access center.

ACCESSING CURATED PPMI DATA

1. After you've registered to access the MJFF data access center, log in here:
<https://neuroshare.michaeljfox.org/>
2. Once logged in, you will see a section called **Available Studies**. Locate the row in this table with PPMI and click the **Request Access** button in the Curated Data column.
3. After clicking the **Request Access** button, you'll be brought to a screen where you'll be prompted to enter your login credentials for the PPMI database at the Laboratory of Neuro Imaging (LONI).
 - **PLEASE NOTE:** You must be a registered PPMI database user in LONI in order to access the curated PPMI data through the MJFF data access center. If you do not have access to the PPMI database, you may apply for access here: <http://www.ppmi-info.org/access-data-specimens/download-data/>
 - If you do not remember your login credentials for the PPMI database, you may recover your account email address and/or password here: <http://www.ppmi-info.org/access-data-specimens/download-data/>
4. Once your LONI credentials are confirmed, you will see that PPMI has been added to the **My Studies** section of the MJFF data access center, and that you now have the option to download curated data in .csv or .txt format and to access curated data in tranSMART.
 - If you are accessing curated PPMI data in the tranSMART instance, please refer to the [tranSMART Foundation's training resources](#) for guidance on how to navigate the instance. These training resources contain information on how to examine the data in tranSMART, how to export the data from the tranSMART instance, and more.

UPLOADING TRANSMART-READY CURATED PPMI DATA INTO LOCAL INSTANCE

The curated files are ready for loading in the tranSMART platform and will work with tM DataLoader ([github](#)). If you are planning to use another ETL loader, please be advised that some changes to a Mapping file may be required to load the files. Please refer to Loading_tM_data_files_into_internal_instance_v1 document for additional loading instructions. Additional training and manual materials could be found [here](#).

RESOURCES AND HELPFUL HINTS

- While the tranSMART instance should work for all modern browsers, the recommended browsers are the latest versions of Chrome or Firefox.
- If you have ports 8181..8199 blocked on your network, then your connection to tranSMART will be refused. Please contact your IT department to open the ports and try again.
- For additional questions on accessing the tranSMART instance or the data access center, please consult the [FAQ page](#) or email techsupport@ranchobiosciences.com.
- The following PPMI study materials can be found in the [Research Documents & SOPs](#) section of the [PPMI website](#):
 - Study protocol



- Schedule of activities
 - Case report forms (CRFs)
- For questions on the PPMI study and/or data collection methods (non-tranSMART- or data access center-related questions), please email ppmi@indd.org.
- For questions about accessing PPMI biospecimen, please email resources@michaeljfox.org.