PPMI Online

PPMI Website  +  PPMI Repository  =  PPMI Online
PPMI Data Repository
Data Ingestion

• Clinical Data from CTCC
  – Demographics & Medical History
  – Assessments & Exams
  – Laboratory Procedures

• Image Data from IND
  – MRI
  – DTI
  – SPECT

• Biospecimen Data to/from Coriell (in progress)
  – Sample distribution requests
  – Inventory updates
PPMI Website

Home Page
- Overview
- Status
- News
- Quicklinks
  - Data Request
  - Biosample Request
PPMI Website

Study Design Page

- Protocols
- Manuals
- SOPs
PPMI Newsletter

- Email sign-up subscription
- Weekly distribution
Data Dissemination

1. Data Use Application
2. Data Use Application Review
3. Data Use Authorization
4. Access Data
Data Dissemination

• Data Use Applications
  – Online application
  – Online review

• Biospecimen Use Applications
  – Online application
  – Online review

• Downloads
  – Search
  – Download Data
  – Download Documents
Accessing 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.

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.

APPLY FOR DATA ACCESS

LOGIN
New Users: Apply

PPMI Data Use Agreement

I request access to data collected by The Parkinson's Progression Markers Initiative (PPMI) for the purpose of scientific investigation, teaching or the planning of clinical research studies and agree to the following terms:

1. I will receive de-identified data and will not attempt to establish the identity of, or attempt to contact any of the PPMI subjects.
2. I will not further disclose these data beyond the uses outlined in this agreement and my data use application.
3. I will require anyone on my team who utilizes these data, or anyone with whom I share these data to comply with this Data Use Agreement by registering with the PPMI database and agreeing to these terms.
4. I will accurately provide the requested information for persons who will use these data and the analyses that are claimed using these data.
5. I will respond promptly and accurately to annual requests to update this information.
6. I will comply with any rules and regulations imposed by my institution and its institutional review board in requesting these data.
7. I will comply with the PPMI Intellectual Property (IP) policy that states:
   a. Rights to any non-PPMI IP, "Background IP" that a researcher uses in analyzing or manipulating PPMI data, information, biopspecimens, materials or results ("Study Materials") may not be claimed by any other researcher or institution.
   b. No researcher or institution may claim any IP rights to any Study Materials or inventions arising out of the Study Materials, and;
   c. Researchers who publish or present analyses of Study Materials will make these freely available without charge to the research community through the PPMI website, when not prohibited by journal copyright terms and conditions.

If I publish abstracts using data from PPMI, I agree to the following:
8. I will cite PPMI as the source of data and the PPMI funding sources in the abstract as space allows.
9. Group authorship of PPMI will not be cited in the authorship line of the abstract.
10. I will upload abstracts onto the PPMI website for registered users to see either as they are accepted or after they are presented.
11. I will prepare "by" abstracts to be posted on the PPMI website of analyses that I am performing with PPMI data.

If I publish manuscripts using data from PPMI, I agree to the following:
12. On the author line of the manuscript, after the named authors, I will include the phrase "and the Parkinson’s Progression Markers Initiative" with an asterisk referring to the following statement and list of names:
   * Data used in the preparation of this article were obtained from the Parkinson’s Progression Markers Initiative (PPMI) database (www.ppmi-info.org). As such, the investigators within PPMI contributed to the design and implementation of PPMI and/or provided data but did not participate in the analysis or writing of this report. PPMI investigators include (complete listing at PPMI site).
13. I will include language similar to the following in the methods section of my manuscripts in order to accurately acknowledge data gathering by the PPMI personnel. Depending upon the length and focus of the article, it may be appropriate to include more or less than the examples below, however.
Returning Users: Sign In

PARKINSON'S PROGRESSION MARKERS INITIATIVE

Play a Part in Parkinson's Research

PPMI @LONI

PROJECTS | SEARCH | ARCHIVE | DOWNLOAD | MANAGE | LONI Home

Don't get lost - learn about the NEW IDA MENU

Parkinson's Progression Markers Initiative

The mission of the Parkinson's Progression Markers Initiative (PPMI) is the identification of biomarkers of Parkinson's disease progression. Information generated by the study will aid the development of more effective treatments for Parkinson's disease as well as better ways to quantify its progression.

Participant Gender Distribution

<table>
<thead>
<tr>
<th>Control</th>
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<tr>
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</tr>
<tr>
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</table>

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REQUEST SPECIMENS

A critical component of PPNI is the standardized, longitudinal collection of biospecimens, which include plasma, serum, blood, cerebrospinal fluid (CSF), DNA and RNA. An inventory of the biospecimens is available through the PPNI database and can be reviewed by investigators interested in incorporating PPNI samples in their research. Please note that PPNI samples can only be used for biomarker verification studies.

Application Process to Request Specimens

Researchers interested in requesting specimens are encouraged to review the Process for Requesting Specimens. Researchers requesting specimens must agree to the Biospecimens Use Agreement and the Publications Policy. Click the button below to read more about the Process for Accessing Stored Specimens and to begin the Request Process.

Before starting the specimen request process, click here to download a template for the Letter of Intent.

Research Funding for Specimen Studies

Researchers requesting biospecimens may also apply for funding from The Michael J. Fox Foundation (MJFF). The review processes for PPNI biospecimens access and MJFF funding of research are separate processes: approval for use of PPNI biospecimens does not guarantee MJFF funding. MJFF has launched a Biomarker Development Funding Program that may support investigators who are approved to use samples from PPNI. Click here to learn more about requesting funding from MJFF for biospecimen research using the PPNI samples.

Ongoing Specimen Analyses and Other Resources

A listing of preliminary analyses specified by the Steering Committee and performed by PPNI cores, as well as analyses performed by additional investigators will be listed in the Ongoing Analyses section of this site (expected to be live Spring 2011). Investigators who are granted samples from PPNI agree to update this information annually, providing the research public with a comprehensive list of the latest findings coming out of PPNI.

Researchers who are interested in reviewing the PPNI collection, processing and storage protocols for biospecimens should review the Biologics Manual and other Research Documents and SOP’s.

ALSO IN THIS SECTION

- Download Data
- Data & Specimens FAQ
Request Specimens Process
Request Specimens Application

Biospecimen Application Form - Stage 1 of 2: Letter of Intent

The biospecimen request process is divided into two stages: the Letter of Intent stage and the Full Proposal stage. Applicants positively reviewed at the Letter of Intent Stage will be invited to submit a Full Proposal. The overall process is summarized in the diagram below.

**Step 1: Biospecimen Use Agreement**

Please read the terms of use agreement below and provide your institution email address. After agreeing to the terms of the PPMI Biospecimen Use Agreement you will receive an email with a link to the Letter of Intent application form. Please note: By selecting “I Agree” below, you agree to submit all data generated from analyses of PPMI biospecimens to the PPMI Data and Publication Committee (DPC) upon completion of your analyses. You also agree to allow the DPC to incorporate this raw data into the PPMI database.

I request access to biospecimens collected by The Parkinson's Progression Markers Initiative (PPMI) for the purpose of scientific investigation and agree to the following terms:

1. I will receive de-identified biospecimens and will not attempt to establish the identity of, or attempt to contact any of the PPMI subjects.
2. I will not share or use these specimens beyond the uses outlined in this agreement and my proposal for access.
3. I will require anyone on my team who utilizes these biospecimens to comply with this Biospecimen Use Agreement by signing this agreement.
4. I will accurately provide the requested information for persons who will use these biospecimens and the analyses that are planned using these biospecimens.
5. I will respond promptly and accurately to annual requests to update this information.
6. I will comply with any rules and regulations imposed by my institution and its institutional review board in requesting these biospecimens.

Email Address:  

[Agreement Options: I Disagree / I Agree]  

SUBMIT

Biospecimen Inventory Summary

(Updated 04-26-2011)

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<th>Visit</th>
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</thead>
<tbody>
<tr>
<td>Consent</td>
<td>59</td>
<td>41</td>
</tr>
</tbody>
</table>
158 image sets match your criteria: Research Group = All; Sex = Both; Modality = MRI; image count = 500

Your access level: ADNI (MEMBER), FE (MEMBER), ICBM (MANAGER), NBLP (DBA), PAD (MANAGER), PPMI (GUEST)
Access to data is controlled by each project's leader. Click the Projects link above for additional information.

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<th>Slice Thickness</th>
<th>Acquisition Plane</th>
<th>View*</th>
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# Baseline Data Summary

**Variable** | **PD Subjects** | **Healthy Controls**
--- | --- | ---
Female(n) | 23 | 20
Male(n) | 38 | 23
Subjects with Family Members with PD(n) | 16 | (n/a)
Subjects with No Family Members with PD(n) | 45 | (n/a)

| Variable | **Mean** | **Range** | **Mean** | **Range**
--- | --- | --- | --- | ---
Age (Years) | 61.0 | 35 - 83 | 59.2 | 31 - 80
Years of Education | 16.2 | 12 - 26 | 16.7 | 12 - 20
Duration of Disease (Months) | 8.9 | 0 - 32 | (n/a) | (n/a)
MDS-UPDRS Total | 35.5 | 14 - 65 | 4.1 | 0 - 17
MDS-UPDRS Part I | 1.6 | 0 - 9 | 0.6 | 0 - 4
MDS-UPDRS Part I - Patient questionnaire | 5.2 | 0 - 11 | 2.1 | 0 - 7
MDS-UPDRS Part II - Patient questionnaire | 6.8 | 1 - 15 | 0.2 | 0 - 4
MDS-UPDRS Part III | 21.9 | 9 - 39 | 1.2 | 0 - 10
Hohn & Yahr | 1.7 | 1 - 3 | 0.0 | 0 - 1
Modified Schwab & England ADL | 92.6 | 60 - 100 | (n/a) | (n/a)
UPSI - Total Score | 23.2 | 6 - 39 | 35.0 | 21 - 40
MoCA Score* | 26.9 | 0 - 30 | 28.4 | 27 - 30
GDS Score | 2.3 | 0 - 10 | 0.8 | 0 - 5
## Baseline Cognitive Data

### Baseline Cognitive Data

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<thead>
<tr>
<th>Variable</th>
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### Mean and Range

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<td></td>
<td>0 - 32</td>
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<td>HVLT Immediate Recall</td>
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<td>HVLT Delayed Recognition Hits</td>
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<td>Benton Judgment of Line Orientation Score</td>
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<td>Letter Number Sequencing Raw Score</td>
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<td>Semantic Fluency Total Score</td>
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<td>27 - 30</td>
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### QUIP Positive-Gambling(n)

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<td>QUIP Positive-Playing(n)</td>
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<td>QUIP Positive-Hobbies(n)</td>
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# Baseline Specimen Data

## Baseline Specimen Collection

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<td>Subjects with Family Members with PD(n)</td>
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<td>(n/a)</td>
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<tr>
<td>Subjects with No Family Members with PD(n)</td>
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<table>
<thead>
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<td>Age (Years)</td>
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<td>35 - 83</td>
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<td>12 - 26</td>
<td>16.7</td>
<td>12 - 20</td>
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<tr>
<td>Duration of Disease (Months)</td>
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<td>0 - 32</td>
<td>(n/a)</td>
<td>(n/a)</td>
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<th>Mean Volume</th>
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<td>Urate</td>
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<td>13.4</td>
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What’s Next

- **ppmi-info.org**
  - Searchable publications page
  - Data analysis methods page
  - Improving ppmi-info.org based on analytics and surveys***

- **PPMI repository**
  - Data Exploration interface
  - Additional biospecimen sharing components
What’s Next

• Ongoing Analysis
What’s Next

- Usage stats