

# Data Access & Publication



PARKINSON'S  
PROGRESSION  
MARKERS  
INITIATIVE

Play a Part in Parkinson's Research



# PPMI Data Access & Publication

PPMI study data access – goal to make data rapidly and widely available via the [PPMI-info.org](http://PPMI-info.org)

PPMI publications – encourage publication of PPMI data



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# PPMI Data Access & Publication committee

- David Standaert (Chair)
- Arthur Toga
- Chris Coffey
- Robert Hauser
- Werner Poewe



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# PPMI Data Access & Publication

## Data & Publication Committee (DPC)

- Oversight of access to PPMI Database
  - Simple online process
- Review publications using PPMI data
  - Review that the author/s have followed the the PPMI Data Use Agreement
  - Meet PPMI publication standards
    - Properly cite and acknowledge the PPMI study
  - Not a review of scientific merit
  - Track PPMI publications



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# PPMI Data Access & Publication

- PPMI data was publicly available after first 50 subjects were enrolled - March 2011
  - Subject data is available in close to 'real time'
  - functionality and content continues to expand and improve
- Data from PD & healthy subjects acquired at PMI sites
  - Clinical data
    - demographic, motor and non-motor, cognitive and neurobehavioral
  - Imaging data
    - DAT, DTI and MRI
  - Blood chemistry and hematology
  - Subject assessments
  - Biospecimen inventories
    - serum, plasma, whole blood, CSF, DNA, RNA and urine
- Acquiring access to PPMI data is a quick & simple online process



# Data Access & Publication

## Getting Access to the PPMI data



- Click on the **DOWNLOAD DATA** button on PPMI website
- Complete a very brief e-form
- Process is available 24/7 with a quick turnaround & grants access to most people

A screenshot of the PPMI website's "Download Data" page. The page has a navigation bar at the top with links: "About PPMI", "Study Design", "Access Data &amp; Specimens", "PPMI News", and "Get Email Updates". Below the navigation bar is a secondary bar with links: "PPMI Qualification Study", "Request Specimens", "Download Data", and "Data &amp; Specimens FAQ". The main content area is titled "DOWNLOAD DATA" and contains a paragraph explaining that qualified researchers can obtain access to clinical, imaging, and biomarker data. It is divided into two columns: "New Users Apply Now:" and "Registered Users:". The "New Users" column includes instructions to submit an online application, sign a Data Use Agreement, and comply with the study's Publications Policy, with an "APPLY FOR DATA ACCESS" button. The "Registered Users" column includes a login form with fields for "Email:" and "Password:", a "LOGIN" button, and a link for "Forgot your login and password?". To the right of the main content is a vertical sidebar with four yellow buttons: "REQUEST SPECIMENS", "for PROSPECTIVE PARTICIPANTS", "for PRACTITIONERS", "for INDUSTRY PARTNERS", and "for RESEARCHERS". At the bottom of the page, there is a section titled "Ongoing Data Analyses and Other Resources" with text about annual updates and a link to the "Data &amp; Specimens FAQ".

Sign – up Today ...**Sign – up Today**...Sign – up Today....**Sign – up Today**...