



**National Institute of Neurological Disorders and Stroke (NINDS)
Parkinson's Disease Biomarkers Program (PDBP)
NON-GENETIC/NON-GENOMIC DATA USE AGREEMENT**

I (the undersigned) request access to data (non-genetic and non-genomic) collected by the NINDS Parkinson's Disease Biomarkers Program (PDBP) for the purpose of scientific investigation, teaching or the planning of clinical research studies and agree to the following terms.

1. I will receive access to de-identified data and will not attempt to establish the identity of, nor attempt to contact any of the PDBP subjects, their physicians, nor their family members.
2. I will not attempt to make direct contact with PDBP PIs or staff at sites concerning additional information regarding individual subjects.
3. I will not further disclose these data beyond the uses outlined in this agreement and my data use application and understand that redistribution of data in any manner is prohibited.
4. I will require anyone on my team, at my institution, who utilizes these data to comply with this data use agreement.
5. I will respond promptly and accurately to annual requests to update information regarding the unpublished results and publications arising from use of this data.
6. I will comply with any rules and regulations imposed by my institution and its institutional review board in requesting these data; I realize that IRB approval is not required by the NINDS, because these data are de-identified. However, if there are local requirements at my institution, they are my responsibility.
7. If I publish abstracts using data from PDBP, I will cite PDBP as the source of data and the NINDS-PDBP funding sources in the abstract as space allows.
8. If I publish manuscripts using data and/or biospecimens from PDBP, I agree to add the following to the Acknowledgements section: *"Data and biospecimens used in preparation of this manuscript were obtained from the Parkinson's Disease Biomarkers Program (PDBP) Consortium, supported by the National Institute of Neurological Disorders and Stroke at the National Institutes of Health. Investigators include: Roger Albin, Roy Alcalay, Alberto Ascherio, Thomas Beach, Sarah Berman, Bradley Boeve, F. DuBois Bowman, Shu Chen, Alice Chen-Plotkin, William Dauer, Ted Dawson, Paula Desplats, Richard Dewey, Ray Dorsey, Jori Fleisher, Kirk Frey, Douglas Galasko, James Galvin, Dwight German, Lawrence Honig, Xuemei Huang, David Irwin, Kejal Kantarci, Anumantha Kanthasamy, Daniel Kaufer, James Leverenz, Carol Lippa, Irene Litvan, Oscar Lopez, Jian Ma, Lara Mangravite, Karen Marder, Laurie Orzelius, Vladislav Petyuk, Judith Potashkin, Liana Rosenthal, Rachel Saunders-Pullman, Clemens Scherzer, Michael Schwarzschild, Tanya Simuni, Andrew Singleton, David Standaert, Debby Tsuang, David Vaillancourt, David Walt, Andrew West, Cyrus Zabetian, Jing Zhang, and Wenquan Zou. The PDBP Investigators have not participated in reviewing the data analysis or content of the manuscript."*
9. I will submit my manuscript prior to Journal publication to the PDBP Steering Committee (via PD-Pubs@ninds.nih.gov) who will verify within 5 days that the PDBP is appropriately acknowledged. If this time elapses without notice from the PDBP Steering Committee Representatives, I may proceed with the paper.
10. I will provide either the manuscript or the full citation of all published manuscripts to the PDBP Data Access Committee (DAC) upon acceptance of manuscripts. Manuscripts will be used by the DAC for internal reference only. Citations will be listed on the PDBP DMR website and available to the public using PubMed format.



11. I will ensure that Investigators who utilize PDBP data use appropriate administrative, physical and technical safeguards to prevent use or disclosure of the data other than as provided for by this Agreement.
12. I will report any use or disclosure of the data not provided for by this Agreement of which I become aware within 5 days of becoming aware of such use or disclosure.
13. All public announcements of research done with this data, for example, press releases, social media discussions, will acknowledge NINDS as the funder of the data collection and PDBP as the source of the data, in total or in part, as is appropriate.

IMPORTANT NOTE: It is the policy of the Parkinson's Disease Biomarkers Program (PDBP) to make analyzed data available to investigators as quickly as possible. However, data analysis for this project is expected to take years as methods for analysis of these datasets evolve. Therefore, I understand that any processed data that I download might be preliminary and that results may change as new methods of analysis are implemented. Finally, because "preliminary data" will be posted on the database, in the event that I download data from the PDBP database for the purposes of analysis and future publication in the form of abstracts and/or publications, I will note any defined version of the data I download, and I will do due diligence to check the database to determine if updated data has been provided prior to submission of any material for publication.

I understand that failure to abide by these guidelines will result in termination of my privileges to access PDBP data.

Signature of User

Name (Printed)

Institution (Printed)

Date (Printed)