

PPMI Biospecimen Use Agreement

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 I will not transfer these specimens or their derivatives for any profit.
- 3. I will require anyone on my team who utilizes these biospecimens to comply with this Biospecimen Use Agreement by having them sign this agreement.
- 4. I will not, and will not allow, use of biospecimens in humans, for diagnostic purposes involving human subjects, in the manufacture of any products except in connection with my MJFF approved research project, or directly for any therapeutic use.
- 5. If I receive peripheral mononuclear blood cells (PBMCs) and use them to create induced pluripotent stem cells (iPSCS), I will not directly or indirectly use the iPSCs to derive or make any human gamete or gamete precursor cell.
- 6. I will accurately provide the requested information for persons who will use these biospecimens and the analyses that are planned using these biospecimens.
- 7. I will respond promptly and accurately to annual requests to update this information.
- 8. I will comply with any rules and regulations imposed by my institution and its institutional review board in requesting these biospecimens.
- 9. 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, biospecimens, 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.

In certain extraordinary situations, PPMI may grant a PPMI user an exception to the PPMI IP Policy. All requests for exceptions to the PPMI IP Policy are reviewed by the PPMI IP Policy Exception Review Committee (Click here to read our Conflict of Interest statement). The committee meets every other month to review applications. All applications submitted to the committee will be treated confidentially. To read more about which situations may be eligible to receive an exception to the PPMI IP Policy or to submit a request for an exception to the PPMI IP Policy Exception Review Committee, click here. Please note that applicants must have an active PPMI database account to submit a request for an exception to the PPMI IP Policy. If you do not have an active PPMI database account, you may apply for one by completing the online application form here.

- 10. If I seek to publish manuscripts or abstracts on analyses of PPMI biospecimens, I will comply with the PPMI Publications Policy, including the following:
 - a. I will submit all manuscripts and abstracts to the PPMI Data and Publications Committee (DPC) *prior to* submitting to a journal or conference. This review will not be a scientific review but is intended to ensure that all manuscripts and abstracts using PPMI data adhere to the PPMI Publications Policy. The DPC will maintain confidentiality of the manuscript and will complete its review within one week of submission.
 - b. I will cite PPMI as the source of the data and biospecimens and the PPMI funding sources within the manuscript of acknowledgements:
 - "Data biospecimens used in the analyses presented in this article were obtained from the Parkinson's Progression Markers Initiative (PPMI) (www.ppmi-info.org/access-data-specimens/download-data). As such, the investigators within PPMI contributed to the design and implementation of PPMI and/or provided data and collected biospecimens, but did not participate in the analysis or writing of this report. For up-to-date information on the study, visit www.ppmi-info.org."
 - "PPMI a public-private partnership is funded by The Michael J. Fox Foundation for Parkinson's Research and funding partners, including [list the full names of all PPMI funding partners found at https://www.ppmi-info.org/about-ppmi/who-we-are/study-sponsors]."
 - c. I will provide the PPMI DPC with full citations and copies of all published manuscripts upon acceptance of manuscripts so that they may be listed on the PPMI website.
 - d. I will notify the PPMI DPC after abstracts or posters are presented so that they may be posted to the PPMI website for users to see,
- 11. I will submit data generated from analyses of PPMI biospecimens to the PPMI Bioinformatics Core at the Laboratory of NeuroImaging (LONI) upon completion of my analyses. I understand that the PPMI Steering Committee and/or Biospecimen Review Committee may choose to incorporate the raw data into the PPMI database after a 45-day sequester period.
- 12. I will ensure that Investigators who utilize PPMI biospecimens use appropriate administrative, physical, and technical safeguards to prevent use of the biospecimens other than as provided for by this agreement and outlined in the application protocol.
- 13. I will report any use or disclosure of the biospecimens not provided for by this agreement of which I become aware within 15 days of becoming aware of such use or disclosure.

I understand that failure to abide by these guidelines will result in termination of my privileges to access PPMI data and/or biospecimens.

The Michael J. Fox Foundation maintains the right to modify terms of this agreement and may do so by posting notice of such modifications on this page. Any modification made is effective immediately upon posting the modification (unless otherwise stated). You should visit this page periodically to review the current use agreement terms.