

## AMP PD Data Use Agreement

I request access to data available through the AMP PD Knowledge Platform (AMP PD Data) for scientific investigation, teaching or the planning of clinical research studies and agree to the following terms:

1. I acknowledge and agree that this AMP PD Data Use Agreement (Agreement or DUA) grants me permission as set forth below to use the AMP PD Knowledge Platform and data contained within and describes my obligations with respect to the AMP PD Knowledge Platform and data.
2. It is the policy of AMP PD to make analyzed data available to investigators as quickly as possible. Data analysis for the AMP PD Project is expected to take years as methods for data analysis evolve. Therefore, I understand that any curated data and/or results that I access might be preliminary. Finally, because “preliminary data” will be posted on the database, in the event that I download data from the AMP PD Knowledge Platform for the purposes of analysis and future publication in the form of abstracts, manuscripts, or other publications, I will (a) note in such abstracts, manuscripts, or other publications the defined version of the data used in my analysis and the date of download, (b) prior to my submission of any material for publication, do due diligence to check the AMP PD Knowledge Platform to determine if updated data is available, and (c) if the data is updated, note in such material for publication that the data has been updated in the AMP PD Knowledge Platform.
3. I will have access to de-identified data and will not attempt to establish the identity of, nor attempt to contact, any of the subjects included in the BioFIND Clinical Study, The Harvard Biomarker Study (HBS), Parkinson’s Progression Markers Initiative (PPMI), or the Parkinson’s Disease Biomarkers Program (PDBP) or subjects from any other studies (collectively, the “Studies”), the data from which is added to the AMP PD Knowledge Platform.
4. I will not attempt to directly contact the cohort Principal Investigators (PIs) or staff associated with the Studies concerning additional information regarding individual subjects, provided that, for clarity, contacts that are not specifically related to individual subjects are permitted.
5. I will use the AMP PD Knowledge Platform solely to access and analyze the AMP PD Data in accordance with this Agreement.
6. I will not disclose or use these data beyond the permitted disclosures and uses outlined in this Agreement. I will require anyone on my team who wants to utilize the AMP PD Data, or anyone with whom I will share these data to comply with this Agreement by becoming a registered user of the AMP PD Knowledge Platform and agreeing to these terms through signing of the DUA. I may disclose these data to any individuals who are registered users of the AMP PD Knowledge Platform.
7. I will use appropriate administrative, physical and technical safeguards to prevent use or disclosure of the data other than as provided for by this Agreement.

8. Upon request by the AMP PD Access and Compliance Team (AMP PD ACT), I will provide accurate information regarding persons who will use the AMP PD Data and the analyses that are planned with these data and I will respond promptly and accurately to annual requests by the AMP PD ACT to update this information.
9. I will comply with any rules imposed by my institution and its institutional review board, as well as any federal, state and local laws and regulations, in each case, that apply to the use of these data, provided such institutional rules do not conflict with the obligations owed by me under this Agreement.
10. I acknowledge that the data included in the AMP PD Knowledge Platform was generated under and is subject to an existing arrangement that has the following AMP PD Intellectual Property Policy that states: "AMP PD users agree not to file patent applications on research discoveries made using the AMP PD Data, except in the rare instance when a consensus of FNIH and the AMP PD Steering Committee and AMP PD Executive committee agree that it is in the best interests of the partnership and public health to do so. Intellectual property developed under NIH awards are subject to applicable Federal law, regulation, and NIH policy." Accordingly, it is in the rare instance that the AMP PD Partnership, through an approval protocol, will deem that it is in the best interest of the AMP PD Partnership and the public health to grant an exception. If an exception is granted, I agree to grant the funding partners of the AMP PD Partnership a nonexclusive, worldwide, royalty-free, sublicensable license to use and/or disclose the intellectual property rights therein for noncommercial research purposes.
11. I understand in accessing the AMP PD Knowledge Platform I am not granted any intellectual property rights and I will not seek any right, title or interest in the clinical data, analysis results, or other intellectual property uploaded into the AMP PD Knowledge Platform that is owned by other individuals or entities without the express written consent of the individuals or entities who uploaded the information to AMP PD.
12. I agree, subject to Section 10 above, that all data and discoveries generated by me from analyses of AMP PD Data in the AMP PD Knowledge Platform (collectively, the "Study Materials Results") will become and be deemed part of the public domain through the AMP PD Knowledge Platform. I will not seek intellectual property protection of the Study Materials Results and will make the Study Materials Results freely available without charge to the research community through the AMP PD Knowledge Platform.
13. By accessing the AMP PD Knowledge Platform, I waive any and all claims against AMP PD and its research partners with respect to my use of the AMP PD Knowledge Platform or the AMP PD Data.
14. If I seek to publish manuscripts incorporating AMP PD Data or Study Materials, I agree to comply with the AMP PD Publications Policy guidelines, including sending manuscripts to the AMP PD Publications Committee (PC) for administrative review prior to publication of a final manuscript.

15. In my manuscripts and presentations incorporating AMP PD Data or Study Materials, I will acknowledge the cohorts PPMI, BioFIND, PDBP, and HBS personnel and other cohorts who provided AMP PD Data and/or the funding of the Studies, and will include language in manuscripts similar to the following:

### **AMP PD Acknowledgement**

"Data used in the preparation of this article were obtained from the AMP PD Knowledge Platform. For up-to-date information on the study, <https://www.amp-pd.org>.

"AMP PD – a public-private partnership – is managed by the FNIH and funded by Celgene, GSK, the Michael J. Fox Foundation for Parkinson's Research, the National Institute of Neurological Disorders and Stroke, Pfizer, and Verily.

### **AMP PD Cohort Acknowledgements**

"Clinical data and biosamples used in preparation of this article were obtained from the Fox Investigation for New Discovery of Biomarkers (BioFIND), the Harvard Biomarker Study (HBS), the Parkinson's Progression Markers Initiative (PPMI), the Parkinson's Disease Biomarkers Program (PDBP), the International LBD Genomics Consortium (iLBDGC), the LRRK2 Cohort Consortium (LCC), and the STEADY-PD III Investigators.

"BioFIND is sponsored by The Michael J. Fox Foundation for Parkinson's Research (MJFF) with support from the National Institute for Neurological Disorders and Stroke (NINDS). The BioFIND Investigators have not participated in reviewing the data analysis or content of the manuscript. For up-to-date information on the study, visit [michaeljfox.org/news/biofind](http://michaeljfox.org/news/biofind)."

"The Harvard NeuroDiscovery Biomarker Study (HBS) is a collaboration of HBS investigators [full list of HBS investigator found at <https://www.bwhparkinsoncenter.org/biobank/> and funded through philanthropy and NIH and Non-NIH funding sources. The HBS Investigators have not participated in reviewing the data analysis or content of the manuscript."

"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 of the PPMI funding partners found at [www.ppmi-info.org/fundingpartners](http://www.ppmi-info.org/fundingpartners)]. The PPMI Investigators have not participated in reviewing the data analysis or content of the manuscript. For up-to-date information on the study, visit [www.ppmi-info.org](http://www.ppmi-info.org)."

"Parkinson's Disease Biomarker Program (PDBP) consortium is supported by the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health. A full list of PDBP investigators can be found at <https://pdbp.ninds.nih.gov/policy>. The PDBP Investigators have not participated in reviewing the data analysis or content of the manuscript."

"Genome Sequencing in Lewy Body Dementia and Neurologically Healthy Controls: A Resource for the Research Community." was generated by the International LBD Genomics Consortium (iLBDGC), under the co-directorship by Dr. Bryan J. Traynor and Dr. Sonja W. Scholz from the Intramural Research Program of the U.S. National Institutes of Health. The iLBDGC Investigators have not participated in reviewing the data analysis or content of the manuscript. For a complete list of contributors, please see: bioRxiv 2020.07.06.185066; doi: <https://doi.org/10.1101/2020.07.06.185066>."

"The LRRK2 Cohort Consortium (LCC) was created to assemble and study groups of people with and without Parkinson's disease who carry mutations in the LRRK2 gene. The LRRK2 Cohort

Consortium is coordinated and funded by The Michael J. Fox Foundation for Parkinson's Research. The investigators within the LCC contributed to the design and implementation of the LCC and/or provided data and/or collected biospecimens, but did not necessarily participate in the analysis or writing of this report. The full list of LCC investigators can be found at [www.michaeljfox.org/lccinvestigators](http://www.michaeljfox.org/lccinvestigators)."

"STEADY-PD III is a 36-month, Phase 3, parallel group, placebo-controlled study of the efficacy of isradipine 10 mg daily in 336 participants with early Parkinson's Disease that was funded by the National Institute of Neurological Disorders and Stroke (NINDS) and supported by The Michael J Fox Foundation for Parkinson's Research and the Parkinson's Study Group. The STEADY-PD III Investigators have not participated in reviewing the data analysis or content of the manuscript. The full list of STEADY PD III investigators can be found at: <https://clinicaltrials.gov/ct2/show/NCT02168842>."

16. I will provide either (i) a copy of the manuscript upon its acceptance for publication or (2) the full citation of all published manuscripts to the AMP PD Publications Committee. Citations will be listed on the AMP PD website and available to the public through PubMed.
  
17. I ACKNOWLEDGE AND AGREE THAT THE DATA IS PROVIDED AS IS AND NO WARRANTIES, EXPRESS OR IMPLIED, ARE OFFERED AS TO THE MERCHANTABILITY OR FITNESS FOR ANY PURPOSE OF THE DATA PROVIDED UNDER THIS AGREEMENT. THERE ARE NOWARRANTIES OR

- a. REPRESENTATIONS AS TO THE PURITY, ACCURACY, SAFETY OR USEFULNESS OF THE DATA OR THAT THE USE OF THE DATA WILL NOT INFRINGE ANY PATENT OR OTHER PROPRIETARY RIGHT.

I understand that failure to abide by these guidelines may result in termination of my privileges to access the AMP PD Knowledge Platform. [Investigators will be asked to sign this agreement electronically at <https://www.amp-pd.org>]

IN WITNESS WHEREOF, the Parties hereto have duly executed this Agreement as of the Effective Date by their authorized representatives.

\_\_\_\_\_

Name (print): \_\_\_\_\_

Name (sign): \_\_\_\_\_

Title: \_\_\_\_\_

INSTITUTIONAL SIGNING OFFICIAL (if Tier 2 access is requested)

Name (print): \_\_\_\_\_

Name (sign): \_\_\_\_\_

Title: \_\_\_\_\_