

## **Accelerating Medicines Partnership® Parkinson's Disease (AMP® PD) Data Use Agreement**

I request access to data available through the Accelerating Medicines Partnership® (AMP®) Parkinson's Disease (AMP PD) Knowledge Platform 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") 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.
2. I acknowledge that the data contained in the AMP PD Knowledge Platform includes data from both the AMP PD program and the Global Parkinson's Genetics Program (GP2). I acknowledge and agree that this Agreement describes my rights and obligation with respect to data from both programs, collectively referred to as "AMP PD Data" in this Agreement, provided that Section 16 sets forth separate intellectual property policies for each data set.
3. I will have access to de-identified data. I will maintain the AMP PD Data in de-identified form and will not attempt to re-identify the data in any way or establish the identity of any of the subjects who are or may be the sources of the AMP PD Data. If I am in possession of any data that can be used, either alone or in combination with any other information, to re-identify any subjects, I will immediately notify the AMP PD Access and Compliance Team (AMP PD ACT) at [act@amp-pd.org](mailto:act@amp-pd.org) and the GP2 Access and Compliance Team (GP2 ACT) at [act@gp2.org](mailto:act@gp2.org). *Such notification must occur within 24 business hours.*
4. I will not attempt to directly contact the cohort Principal Investigators (PIs) or staff associated with the studies that are part of the AMP PD and GP2 programs, the data from which are added to the AMP PD Knowledge Platform, 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 AMP PD Data beyond the permitted disclosures and uses outlined in this Agreement. I will not sell, rent, lease, loan, or license the AMP PD Data to any third party.
7. I will require anyone with whom I will share relevant AMP PD Data, including others on my team and within my institution, to comply with this Agreement by having them become an approved registered user of the AMP PD Knowledge Platform and agreeing to these terms through signature on or acceptance of this Agreement, as applicable, *prior to my sharing of the data.*
8. I may disclose AMP PD Data only to individuals who are registered users of the AMP PD Knowledge Platform and have the appropriate data access approval for the data I am sharing.
9. I will respond promptly and accurately to annual requests by the AMP PD ACT and the GP2 ACT to update my application information.
10. Should I elect to use the Terra environment for analyses, I agree to abide by the [Terra terms of service](#) developed by the Terra platform operators.

11. Should I elect to download AMP PD Data, my host institution accepts responsibility for the security of the downloaded data, as verified by the institutional signature on this Agreement, for as long as the downloaded data is in existence. I will also provide documentation to the appropriate ACT ([act@amp-pd.org](mailto:act@amp-pd.org) and/or [act@gp2.org](mailto:act@gp2.org)) as to why I am downloading the data. I acknowledge that I will be responsible for all costs associated with the download. I also acknowledge and agree that all obligations with respect to downloaded data as set forth in this Agreement survive the expiration or termination of the Agreement.
12. I will retain control over the AMP PD Data and will use appropriate administrative, physical and technical security safeguards to prevent use or disclosure of the AMP PD Data other than as provided for by this Agreement.
13. I will immediately report any inadvertent data release, including breach of data security or other data management incidents, to AMP PD ACT, [act@amp-pd.org](mailto:act@amp-pd.org), and GP2 ACT, [act@gp2.org](mailto:act@gp2.org). *Such reports must occur within 24 business hours.*
14. I will contact AMP PD ACT, [act@amp-pd.org](mailto:act@amp-pd.org), and GP2 ACT, [act@gp2.org](mailto:act@gp2.org), without undue delay if I suspect that AMP PD Data are improperly shared on the AMP PD Knowledge Platform, if I am concerned that AMP PD Data shared on the AMP PD Knowledge Platform are improperly or incompletely de-identified, or if I suspect unauthorized use of AMP PD Data. *Such contact shall occur within 24 business hours.*
15. 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 my use of AMP PD Data, provided such institutional rules do not conflict with the obligations owed by me under this Agreement. In the presence of such an unresolved conflict, I will cease to use the AMP PD Data until a suitable resolution is identified and implemented and the obligations of this Agreement continue to prevail without hinderance.
16. I acknowledge that the AMP PD program and GP2 have separate intellectual property (IP) policies and agree as follows:
  - a. Data from the AMP PD program were generated under and are 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 the Foundation for the National Institutes of Health (FNIH), the AMP PD Steering Committee and the AMP Executive Committee agree that it is in the best interests of the partnership and public health to do so. Intellectual property developed under National Institutes of Health (NIH) awards are subject to applicable Federal law, regulation, and NIH policy." Accordingly, it is in the rare instance that the AMP PD Steering Committee, through an approval protocol, will deem that it is in the best interest of the AMP PD program and the public health to grant an exception. If an exception is granted, I agree to grant the funding partners of the AMP PD program a nonexclusive, worldwide, royalty-free, sublicensable license to use and/or disclose the intellectual property rights in and to the research discoveries made using the AMP PD Data for noncommercial research purposes.

- b. GP2 has been established as a pre-competitive consortium. All rights to pre-existing IP that is used in connection with the GP2 data will remain with the owner of such IP. GP2 will not acquire any rights in or to any pre-existing IP or improvements thereto. I agree not to file a patent application, copyright, or assert trade secrets or other IP on research discoveries (including improvements to pre-existing IP) made using data from GP2 (except that articles divulging research discoveries may be copyrighted). For example, if I create or improve an algorithm using GP2 data, I will not claim IP on this algorithm. (An “improvement” is a modification to, variation of, or derivation from the original IP.) For more information, please email [act@gp2.org](mailto:act@gp2.org).
17. 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 are owned by other individuals or entities, without the express written consent of the individuals or entities who uploaded the information to the AMP PD Knowledge Platforms.
18. I agree, subject to Sections 16 and 17 above, that all data and discoveries generated by me from analyses of AMP PD Data (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 Platforms.
19. By accessing the AMP PD Knowledge Platform, I waive any and all claims against the AMP PD and GP2 programs, the Foundation for the National Institutes of Health, Inc., the AMP PD funding and research partners, and the GP2 funding and research partners with respect to or arising from my use of the AMP PD Knowledge Platform or the AMP PD Data.
20. It is the policy of the AMP PD and GP2 programs to make analyzed data available to investigators as quickly as possible. Data analysis for the AMP PD and GP2 programs are expected to take years as methods for data analysis evolve. Therefore, I understand that any 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 use or download AMP PD Data 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, 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.
21. If I seek to publish manuscripts incorporating AMP PD Data or Study Materials Results, I agree to comply with the AMP PD Publications Policy guidelines and/or the Publication Policy of the GP2 program, as applicable, including sending manuscripts to the AMP PD Publications Committee and/or the GP2 Steering Committee for administrative review prior to publication of a final manuscript. The administrative review is conducted to ensure compliance with this Agreement and does not constitute editorial control by the AMP PD Publications Committee and GP2 Steering Committee.

22. In my manuscripts and presentations incorporating AMP PD Data or Study Materials Results, I will acknowledge the AMP PD and/or GP2 program(s), AMP PD and/or GP2 funders, and the relevant cohorts who provided data to the AMP PD and/or GP2 programs by including language similar to the following:

AMP PD Acknowledgement:

"Data used in the preparation of this article were obtained from the Accelerating Medicine Partnership® (AMP®) Parkinson's Disease (AMP PD) Knowledge Platform. For up-to-date information on the study, visit <https://www.amp-pd.org>.

"The AMP® PD program is a public-private partnership managed by the Foundation for the National Institutes of Health and funded by the National Institute of Neurological Disorders and Stroke (NINDS) in partnership with the Aligning Science Across Parkinson's (ASAP) initiative; Celgene Corporation, a subsidiary of Bristol-Myers Squibb Company; GlaxoSmithKline plc (GSK); The Michael J. Fox Foundation for Parkinson's Research; AbbVie Inc.; Pfizer Inc.; Sanofi US Services Inc.; and Verily Life Sciences.

"ACCELERATING MEDICINES PARTNERSHIP and AMP are registered service marks of the U.S. Department of Health and Human Services."

AMP PD Cohort Acknowledgements:

"Clinical data and biosamples used in preparation of this article were obtained from the (i) Michael J. Fox Foundation for Parkinson's Research (MJFF) and National Institutes of Neurological Disorders and Stroke (NINDS) BioFIND study, (ii) Harvard Biomarkers Study (HBS), (iii) National Institute on Aging (NIA) International Lewy Body Dementia Genetics Consortium Genome Sequencing in Lewy Body Dementia Case-control Cohort (LBD), (iv) MJFF LRRK2 Cohort Consortium (LCC), (v) NINDS Parkinson's Disease Biomarkers Program (PDBP), (vi) MJFF Parkinson's Progression Markers Initiative (PPMI), and (vii) NINDS Study of Isradipine as a Disease-modifying Agent in Subjects With Early Parkinson Disease, Phase 3 (STEADY-PD3) and (viii) the NINDS Study of Urate Elevation in Parkinson's Disease, Phase 3 (SURE-PD3).

"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/biofind](http://michaeljfox.org/biofind)."

"Genome sequence data for the Lewy body dementia case-control cohort were generated at the Intramural Research Program of the U.S. National Institutes of Health. The study was supported in part by the National Institute on Aging (program #: 1ZIAAG000935) and the National Institute of Neurological Disorders and Stroke (program #: 1ZIANS003154)."

"The Harvard Biomarker Study (HBS) is a collaboration of HBS investigators [full list of HBS investigators 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."

“Data used in preparation of this article were obtained from The Michael J. Fox Foundation sponsored LRRK2 Cohort Consortium (LCC). The LCC Investigators have not participated in reviewing the data analysis or content of the manuscript. For up-to-date information on the study, visit <https://www.michaeljfox.org/biospecimens>.”

“PPMI is sponsored by The Michael J. Fox Foundation for Parkinson’s Research and supported by a consortium of scientific partners: [list the full names of all of the PPMI funding partners found at <https://www.ppmi-info.org/about-ppmi/who-we-are/study-sponsors>]. 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).”

“The 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.”

“The Study of Isradipine as a Disease-modifying Agent in Subjects With Early Parkinson Disease, Phase 3 (STEADY-PD3) is funded by the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health with support from The Michael J. Fox Foundation and the Parkinson Study Group. For additional study information, visit <https://clinicaltrials.gov/ct2/show/study/NCT02168842>. The STEADY-PD3 investigators have not participated in reviewing the data analysis or content of the manuscript.”

“The Study of Urate Elevation in Parkinson’s Disease, Phase 3 (SURE-PD3) is funded by the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health with support from The Michael J. Fox Foundation and the Parkinson Study Group. For additional study information, visit <https://clinicaltrials.gov/ct2/show/NCT02642393>. The SURE-PD3 investigators have not participated in reviewing the data analysis or content of the manuscript.”

#### GP2 Cohort Acknowledgement:

“Data used in the preparation of this article were obtained from Global Parkinson’s Genetics Program (GP2). GP2 is funded by the Aligning Science Against Parkinson’s (ASAP) Initiative and implemented by The Michael J. Fox Foundation for Parkinson’s Research (<https://www.gp2.org>). For a complete list of GP2 members see <http://www.gp2.org>.”

23. I will provide either (i) a copy of the manuscript upon its acceptance for publication or (ii) the full citation of all published manuscripts to the AMP PD Publications Committee and the GP2 Steering Committee. Citations will be listed on the AMP PD and GP2 websites and available to the public through PubMed.
24. Access to the GP2 data components is managed solely by the GP2 ACT, which may notify users of additional GP2-specific data usage requirements from time to time. I agree to comply with all

such GP2-specific requirements immediately upon notification by the GP2 ACT representative. I agree that continued use of GP2 data components after receipt of additional terms constitutes acceptance of those terms.

25. I ACKNOWLEDGE AND AGREE THAT THE AMP PD DATA ARE PROVIDED AS IS AND NO WARRANTIES, EXPRESS OR IMPLIED, ARE OFFERED AS TO THE MERCHANTABILITY OR FITNESS FOR ANY PURPOSE OF THE AMP PD DATA PROVIDED UNDER THIS AGREEMENT. THERE ARE NO WARRANTIES OR REPRESENTATIONS AS TO THE PURITY, ACCURACY, SAFETY OR USEFULNESS OF THE AMP PD DATA OR THAT THE USE OF THE AMP PD DATA WILL NOT INFRINGE ANY PATENT OR OTHER PROPRIETARY RIGHT.
26. I acknowledge and agree that this Agreement will remain in effect for a period of one (1) year from the Effective Date and will automatically expire at the end of this period unless terminated earlier or renewed. For renewals requiring a signature from an Authorized Institution Business Official, I understand that the renewal process will be initiated by communications from AMP PD ACT or GP2 ACT approximately one (1) month prior to the expiration date of this Agreement, and I agree to respond promptly to communications from AMP PD ACT and GP2 ACT. For other renewals, I understand that investigators should sign, date, and submit a new agreement electronically at <https://www.amp-pd.org> within one year of the Effective Date of this Agreement.
27. I acknowledge and agree that this Agreement may be terminated by the AMP PD program or GP2 without cause by providing thirty (30) days written notice to me or the institutional official identified below at the email address(es) provided below. I also understand that the Agreement may be terminated by me or the institutional official identified below by providing thirty (30) days written notice to AMP PD ACT, [act@amp-pd.org](mailto:act@amp-pd.org), and GP2 ACT, [act@gp2.org](mailto:act@gp2.org).
28. I understand that failure to abide by the terms of this Agreement will result in the immediate termination of my privileges to access the AMP PD Data through the AMP PD Knowledge Platform and to use AMP PD Data that has been downloaded in accordance with Section 11 above.
29. Sections 3, 4, 6, 7, 8, 10, 11, 12, 13, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, and 28 of this Agreement will survive expiration or termination of this Agreement.

[Tier 1 limited data access 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.

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Individual Applicant

Last Updated 07.05.2023

Signature: \_\_\_\_\_

Name: \_\_\_\_\_

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

Date: \_\_\_\_\_

Email: \_\_\_\_\_

Phone: \_\_\_\_\_

Authorized Institutional Business Official

Signature: \_\_\_\_\_

Name: \_\_\_\_\_

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

Date: \_\_\_\_\_

Email: \_\_\_\_\_

Phone: \_\_\_\_\_