LRRK2 COHORT CONSORTIUM DATA USE AGREEMENT
(“Data Use Agreement”)

I request access to data collected by The LRRK2 Cohort Consortium (“LCC”) for the purpose of scientific investigation and agree to the following terms of the LRRK2 Data Use Policy:

LRRK2 Cohort Consortium Data Use Policy
Access to data collected by the LCC (“Data”) will be granted according to procedures set forth by the LRRK2 Cohort Consortium Data (“LCD”) Steering Committee and in compliance with this LRRK2 Data Use Policy (“Policy”):

1. All access to Data must be approved in advance by the LCD. Such approval will be granted to scientific researchers, including employees or independent contractors working under the direction of such scientific researchers, and the (non-profit or for-profit) institutions at which approved scientists will conduct their research (“Recipients”).

2. Recipients will be required to agree to the terms and conditions of this Policy prior to receiving access to Data.

3. Access to Data will be granted by the LCD only for scientific research purposes, which may include testing research tools, therapies or cures for commercialization. Requestors will complete a form requesting access to Data which will include, among other things, a description of the intended research use of the Data.

4. Recipients must agree to comply with all rules and regulations imposed by institutions at which Recipients will use the Data, including institution review board (“IRB”) policies and procedures.

5. All Data is deidentified. Access to Data will be granted only on the condition that Recipients will not attempt to establish the identity of, or attempt to contact, subjects participating in the LRRK2 clinical study (“Study”).

6. Data may not be used: (a) for any purpose other than as outlined in a Recipient’s proposal for access; or (b) in any way that conflicts with this Policy or any guidelines established by the LCD. During any time that Recipient is in possession of Data, Recipient must report (i) any important changes to the research purpose or (ii) changes to the principal investigator in charge of the Data included in an application for access to Data (each a “Material Change”), which Material Change will require advance approval from the LCD.
7. Data may not be shared by Recipients with anyone not affiliated with the Recipient institution (each, a “Third Party”), unless advance approval is obtained from the LCD, the proposed Third Party is participating in the research identified in the Recipient’s application for access to the Data and the Third Party agrees in writing to be bound by this Policy.

8. Recipients must respond promptly and accurately to annual requests for updates on use of Data and the progress of the research for which any Data is used.

9. No Recipient or institution receiving Data may claim any intellectual property rights, including, without limitation, patent, copyright, trademark or trade secrets (“IP”) in Data. Neither MJFF nor the LCC may claim IP rights in any Data.

10. No Recipient or institution using Data may claim any IP rights for any invention or new work created in whole or part from Recipient’s use of Data. Recipients will agree to use their best efforts to publicize to the research community any invention or new work useful to Parkinson’s disease researchers created in whole or part from Data, including contacting MJFF for assistance in publicizing such invention or new work. This Section 10 shall not preclude any Recipient from claiming IP rights to any invention or work not involving in any way Recipient’s use of Data (“Background IP”), even if the Data are used to test or analyze the Background IP. Any such Background IP should be identified on Recipients’ proposal requesting access to Data.

11. Any IP claim in violation of Sections 9 or 10 of this Policy shall be void, and Recipient agrees to withdraw any improperly filed IP claim, whether such claim is filed in a court, to a government agency, and/or with a private party.

12. Any publication, presentation or analysis using Data shall be made freely available to the scientific research community without charge, including, at MJFF’s election, through a website maintained by MJFF, unless accepted for publication by a journal of established reputation in the scientific community not controlled by Recipient whose publication policies conflict with this Section 12, in which case such publication may be in accordance with the policies of the journal.

13. Any publication, presentation or analysis using Data by Recipient will cite the LRRK2 Cohort Consortium as the source of the Data and MJFF as funder and coordinator of the LCC. Any publication, presentation or analysis using Data will be submitted to MJFF in advance so that MJFF may verify that Recipient has complied with this Section 13.

14. Any publication, presentation or analysis using Data by Recipient will cite the LCC as the source of the Data and MJFF as funder and coordinator of the LCC. Acknowledgements shall include language similar to the following:

“The MJFF LRRK2 Cohort Consortium is coordinated and funded by The Michael J. Fox Foundation for Parkinson’s Research.”
14.1 Any manuscripts published using LCC Data will include the following on the author line of the manuscript, after the named authors, “the MJFF LRRK2 Cohort Consortium*” with an asterisk referring to the following statement and list of LCC investigator names (found on the LCC website - https://www.michaeljfox.org/page.html?lrrk2-cohort-consortium):

“*Data used in the analyses presented in this article were obtained from the MJFF LRRK2 Cohort Consortium (LCC) (https://www.michaeljfox.org/page.html?lrrk2-cohort-consortium). The investigators within the LCC contributed to the design and implementation of the LCC and/or provided Data but did not necessarily participate in the analysis or writing of this report. LCC investigators include [names of LCC investigators].”

14.2 Within the methods section of any manuscript published using LCC Data, language similar to the following will be included. Depending upon the length and focus of the article, it may be appropriate to include more or less than the example below, however, inclusion of some variation of the language shown below is mandatory.

“Data used in preparation of this article were obtained from the MJFF LRRK2 Cohort Consortium (LCC) (https://www.michaeljfox.org/page.html?lrrk2-cohort-consortium). For up-to-date information on the study, visit https://www.michaeljfox.org/page.html?lrrk2-cohort-consortium.”

15. Any publication, presentation or analysis using Data will be submitted to MJFF in advance so that MJFF may verify that Recipient has complied with these Sections 13 and 14. MJFF may share the publication, presentation or analysis with the LCD. MJFF and the LCC will maintain confidentiality of the manuscript and will complete its review promptly.

16. Any new raw data generated from analyses of Data will be submitted to the LCD upon completion of analyses. The LCD may choose to incorporate the raw data into the LCC database.

Important Note: It is the intent of the LCC to make Data available to investigators as quickly as possible after its receipt by the LCC. Data is locked and updated on a quarterly basis. LCC sites utilized similar, but individual protocols, and therefore, not every site collects the same data points. Furthermore, methods for obtaining data points might differ among LCC sites. The LCC worked to bring a core set of measurements together into one database for large-scale analyses.

I am aware that the Data has limitations, including that the LCC is an ongoing project and I will take this into account in my use of Data.

Because Data may be updated (likely on a quarterly basis), in the event that I download Data for the purposes of analysis and future publication in the form of abstracts and/or publications, I will
note the version of the Data I download, and I will check the database to determine if updated Data has been provided prior to submission of any material for publication.

I agree to report any use or disclosure of the Data not provided for by this Policy of which I become aware within 15 days of becoming aware of such use or disclosure.

I will ensure that any Recipients who utilize LCC Data use appropriate and administrative, physical and technical safeguards to prevent use of the Data other than as provided for by this Data Use Agreement and outlined in the application protocol.

I agree to the terms of this Policy as well as any future changes to this Policy made by the LCD, unless such changes hamper my work. If that is the case, I agree to contact the LCD to discuss such changes to understand the best way to proceed without violating terms of the Policy as amended.

I understand that failure to abide by this agreement will result in termination of my privileges to access LCC Data.

________________________________________
(Signature)

________________________________________
(Print Name)

________________________________________
(Date of signature)