BioFIND Data Use Agreement

I request access to data collected by the Fox Investigation for New Discovery of Biomarkers (“BioFIND”) for the purpose of scientific investigation, teaching, or the planning of clinical research studies and agree to the following terms:

1. I will receive de-identified data and will not attempt to establish the identity of, or attempt to contact any of the BioFIND subjects.
2. I will not further disclose these data beyond the uses outlined in this agreement and my data use application.
3. I will require anyone on my team who utilizes these data, or anyone with whom I share these data to comply with this Data Use Agreement by registering with the BioFIND database and agreeing to these terms.
4. I will accurately provide the requested information for persons who will use these data and the analyses that are planned using these data.
5. I will respond promptly and accurately to annual requests to update this information.
6. I will comply with any rules and regulations imposed by my institution and its institutional review board in requesting these data.
7. I will comply with the BioFIND Intellectual Property (IP) policy that states:
   a. Rights to any non-BioFIND IP (“Background IP”) that a researcher uses in analyzing or manipulating BioFIND data, information, biospecimens, materials or results (“Study Materials”) may not be claimed by any other researcher or institution;
   b. Researchers or institutions may claim IP rights to any Study Materials or inventions arising out of the Study Materials, as long as a non-exclusive license is provided to MJFF for research only purposes; and,
   c. Researchers who publish or present analyses of Study Materials will make these freely available without charge to the research community through the BioFIND website, when not prohibited by journal copyright terms and conditions.
8. If I seek to publish manuscripts or abstracts using data from BioFIND, I will comply with the BioFIND Publications Policy, including the following:
   a. I will submit all manuscripts and abstracts to the BioFIND Data & Publications Committee (DPC) prior to submitting to a journal or conference for administrative review. The DPC will not review submissions for scientific quality, trusting that the peer-review process is the best way to judge the objective quality of a publication. Review of submitted manuscripts and abstracts is guaranteed within two weeks of submission. To submit to the DPC, please email a copy of the manuscript to resources@michaeljfox.org with the subject line “BioFIND Manuscript for DPC Review”.
   b. I will cite BioFIND as the source of data and The Michael J. Fox Foundation for Parkinson’s Research (MJFF) and National Institute of Neurological Disorders and Stroke (NINDS) as the funding sources within the manuscript or acknowledgments:

"Data used in the preparation of this article were obtained from the Fox Investigation for New Discovery of Biomarkers (“BioFIND”) database (http://biofind.loni.usc.edu/). For up-to-date information on the study, visit www.michaeljfox.org/biofind."
“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).”

c. I will provide the BioFIND DPC with full citations and copies of all published manuscripts upon acceptance of manuscripts so that they may be listed on the MJFF website.

d. I will notify the BioFIND DPC after abstracts or posters are presented so that they may be posted to the MJFF website for users to see.

9. I will prepare ‘lay’ abstracts to be posted on the BioFIND website of analyses that I am performing with BioFIND data.

10. I will ensure that Investigators who utilize BioFIND data use appropriate administrative, physical, and technical safeguards to prevent use or disclosure of the data other than as provided for by this Agreement.

11. I will report any use or disclosure of the data not provided for by this Agreement of which I become aware within 15 days of becoming aware of such use or disclosure.

Finally, although the BioFIND clinical database is a “locked” resource, I acknowledge that additional data may be added to the BioFIND database due to additional data analysis and/or analysis of biospecimens. In the event that I download data from the BioFIND database 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 within the publication by specifying the download date.

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