

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.

If I seek to publish abstracts using data from BioFIND, I agree to the following:

8. I will submit all manuscripts to the BioFIND Steering Committee ***prior to submitting to a journal.*** This review will not be a scientific review, but is intended to ensure that the stipulations contained herein are correctly implemented. The Steering Committee will maintain confidentiality of the manuscript and will complete its review within two weeks. To submit abstracts, please email resources@michaeljfox.org with the subject line "BioFIND Publications"
9. I will cite BioFIND as the source of data and MJFF and National Institute of Neurological Disorders and Stroke (NINDS) as the funding sources in the abstract as space allows.
10. I will upload abstracts onto the BioFIND website for users to see either as they are accepted or after they are presented.
11. I will prepare 'lay' abstracts to be posted on the BioFIND website of analyses that I am performing with BioFIND data.

If I publish manuscripts using data from BioFIND, I agree to the following:

12. On the author line of the manuscript, after the named authors, I will include the phrase “the Fox Investigation for New Discovery of Biomarkers*” and will follow all stipulations outlined in the BioFIND Publications Policy.

13. I will include language similar to the following in the methods section of my manuscripts in order to accurately acknowledge data gathering by the BioFIND personnel. 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 the preparation of this article were obtained from the Fox Investigation for New Discovery of Biomarkers database. For up-to-date information on the study, visit www.michaeljfox.org/biofind."

14. I will acknowledge funding from BioFIND in the support acknowledgement section of the manuscript using language similar to the following:

“BioFIND is funded by The Michael J. Fox Foundation for Parkinson’s Research and the National Institute Neurological Disorders and Stroke. “

15. I will submit all manuscripts to the BioFIND Steering Committee prior to submitting to a journal. This review will not be a scientific review, but is intended to ensure that items above are correctly implemented. The Steering Committee will maintain confidentiality of the manuscript and will complete its review within one week. To submit abstracts, please email resources@michaeljfox.org with the subject line “BioFIND Publications”

16. 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.

17. 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.

IMPORTANT NOTE: It is the policy of BioFIND to make data available to investigators as quickly as possible. These data are not locked and therefore may change. I am aware of the limitations of these data prior to using them for scientific purposes and that future results may change as additional data become available.

Finally, because "preliminary data" will be posted on the data base, in the event that I download data from the BioFIND data base 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

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