

S4 Data Use Agreement

I request access to data collected by the System Synuclein Sampling Study (S4) 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 S4 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 S4 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 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 S4 Intellectual Property (IP) Policy that states:
 - a. Rights to any non-S4 IP ("Background IP") that a researcher uses in analyzing or manipulating S4 data, information, biospecimens, materials, or results ("Study Materials") may not be claimed by any other researcher or institution;
 - b. No researcher or institution may claim any IP rights to any Study Materials or patents on new inventions arising out of use of the Study Materials (for clarity, researchers and institutions may claim through use of Study Materials (i) non patent IP rights such as copyrights and trade secrets, and (ii) improvements to pre-existing inventions for which a patent has been issued or patent application has been filed); and,
 - c. Researchers who publish or present analyses of Study Materials will make these freely available without charge to the research community, when not prohibited by journal copyright terms and conditions.

In certain extraordinary situations, S4 may grant a S4 database user an exception to the S4 IP Policy. All requests for exceptions to the S4 IP Policy are reviewed by the S4 Steering Committee. This committee will meet monthly to review all applications received in time for the meeting. All applications submitted to this committee will be treated confidentially. To submit a request for an exception to the S4 IP Policy, please contact resources@michaelifox.org.

Please note that interested applicants must have an active S4 database account to be able to submit a request for an exception to the S4 IP Policy.

8. If I seek to publish manuscripts using data from S4, I agree to follow the guidelines established and written out in the <u>S4 Publications Policy</u>, including sending manuscripts



- to the S4 Steering Committee for administrative review.
- 9. In manuscripts utilizing S4 data, I will acknowledge the work by S4 personnel that went into accumulating the data, as well as funding of the study, and will include language in manuscripts as outlined in the S4 Publications Policy.
- 10. To promote further scholarly productivity, I acknowledge that S4 study leadership may request that I submit data generated from analyses of S4 data upon completion of my analyses. I understand that S4 study leadership may choose to incorporate raw data into the S4 database.
- 11. I will do my best to ensure that Investigators who utilize S4 data use appropriate administrative, physical, and technical safeguards to prevent use or disclosure of the data other than as provided for by this Agreement and will promptly report any use or disclosure of data that does not comply with the guidelines established by this Agreement.

I understand that failure to abide by these guidelines may result in termination of my privileges to access S4 data.

The Michael J. Fox Foundation maintains the right to modify terms of this agreement and may do so by posting notice of such modifications on this page. Any modification made is effective immediately upon posting the modification (unless otherwise stated).