National Institute of Neurological Disorders and Stroke (NINDS)

MYALGIC ENCEPHALOMYELITIS/ CHRONIC FATIGUE SYNDROME (ME/CFS) DATA ACCESS REQUEST AGREEMENT

I (the undersigned) request access to search ME/CFS data owned by NINDS for the purpose of scientific investigation or the planning of research studies in the field of ME/CFS, and agree to the following terms for the search access.

1. I will receive access to de-identified data and will not attempt to establish the identity of, nor attempt to contact any of the ME/CFS research participants, their physicians, nor their family members.
2. I will not attempt to make direct contact with ME/CFS PIs or staff at sites concerning additional information regarding individual participants.
3. I will not further disclose these data beyond the uses outlined in this agreement and understand that redistribution of data, including within my organization, in any manner is prohibited.
4. I will require anyone on my team, at my institution, who utilizes these data to comply with this data use agreement.
5. I will comply with any rules and regulations, including those that might be imposed by my institution and its institutional review board, in requesting these data.
6. I will ensure appropriate administrative, physical, and technical safeguards have been established and will be maintained to prevent use or disclosure of the data other than as provided for by this Agreement.
7. I will report any use or disclosure of the data not provided for by this Agreement of which I become aware within 5 days of becoming aware of such use or disclosure to: ninds-dac@mail.nih.gov

IMPORTANT NOTE: I understand that any processed data that I download might be preliminary and that results may change as new methods of analysis are implemented. Finally, because "preliminary data" will be posted on the database, I will note any defined version of the data I download, and I will do due diligence to check the database to determine if updated data has been provided.

_____
Requestor's Name (Printed)

_____   _____
Requestor's Signature   Date