



Dear Dr. Coller,

I am writing to request permission to participate in the Rockefeller University Bleeding History Phenotyping System Repository (RUBHPSR) maintained by the Rockefeller University Laboratory of Blood and Vascular Biology and the Rockefeller University Informatics Core. I am requesting permission for “Level 2” Access, which is defined as access to my own data, but not to data that have been collected by other investigators and submitted to the RUBHPSR.

In order to participate in the RUBHPSR and collect patient and/or research participant data using the RUBHPSR, I agree to enter into a Collector/Collaborator Agreement. I enter into this agreement with the understanding that data that I enter will be stored on a Rockefeller University server, but will not be included in the aggregated database, and will therefore not be accessible to other investigators. I agree that as a Collector/Collaborator I will abide by the following rules:

- The RUBHPSR will only used by me for research purposes if the protocol describing the research is approved by my institution’s Institutional Review Board (IRB) and/or equivalent regulatory body.
- I will only contribute data to the RUBHPSR from individuals who have given informed consent to have their data entered and shared with other investigators.
- I will not share my access/password to the RUBHPSR with other investigators.
- Individuals whose data are stored in the RUBHPSR will be identified by a password-protected Unique Personal Identification Number (UPIN) provided by the system. No other identifying information will be entered.
- No personal identifying data will be entered into the free text portions of the Phenotype Recording Instrument (PRI).
- I will inform others who request to enter their participant’s data in the RUBHPSR who are not my direct designees that they must enter into Collector/Collaborator and Recipient/Collaborator agreements of their own.
- I will notify you by sending an email message (to collerb@rockefeller.edu) if a research manuscript using data for the RUBHPSR has been accepted for publication and I will acknowledge the RUBHPSR in the publication as follows:” I (we) wish to acknowledge the assistance of the Rockefeller University Bleeding History Phenotype System Repository, which is



supported by a Clinical and Translational Science Award (8 UL1 TR000043) from the National Center for Research Resources of the NIH.”

- I will renew this Agreement annually.
- I have read and agree to the terms of the Disclaimer, Waiver, and Assumption of Risk, namely:

All content, materials, data, and/or information (collectively, “information”) on the Rockefeller University Bleeding History Phenotyping Sytem Repository (“Site”) is collected and/or relied upon for non-clinical, research purposes only. The information should not be used and/or relied upon for making any clinical decisions, including medical prevention, diagnosis and/or treatment. To the fullest extent permitted by law, by accessing and/or using the Site and /or its information, you agree to waive all claims against, and you agree that you will not bring any claim or seek to hold the Rockefeller University Liable under any legal theory, whether in tort (including negligence), contract or otherwise, for damages, including any direct, indirect, special, incidental, and/or consequential damages, relating to the Site and its information.

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In order to retrieve patient or research participant data entered by me or others from the RUBHPSR, I agree to enter into a Recipient/Collaborator Agreement with the RUBHPSR and abide by the rules enumerated below:

- I will receive from the RUBHPSR my own data, but not data that have been collected by other investigators.
- I will not transfer retrieved data to other investigators and/or institutions.

Sincerely,

Signature and Title

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