

Mayo Clinic Mitochondrial Disease Biobank Data and Sample Request

Today's date:

PI's Name:

PI's Institution:

PI's Phone #

PI's E-Mail:

Requestor's Name (If different):

Requestor's Phone #:

Requestor's E-Mail:

Project Name:

IRB number(s) (if available)*:

* Requests can be made without an IRB approved protocol, however no samples or participant-specific data will be distributed until IRB-review has been discussed

Funding Source/Sponsorship:

Industry

Base Budget

Previously Funded Grant

Proposed Grant

Submission Deadline:

☐

Name of Sponsor:

☐☐

Funding Agency:

☐

Funding Agency:

Please provide any specific text you want included in the letter of support for your project:

Has this been reviewed?

☐ NIH Review, ☐ Review Complete, ☐ Under Review

☐ Departmental Review

☐ Other peer-review:

☐ Not yet reviewed. Please describe your plans for project review:

What participant characteristics would you like (for instance, diagnosis, clinical condition, etc.)?

Description of Study (Abstract):

In lay terminology, please provide approximately 2-5 sentences describing how using Biobank resources will benefit you. (This may be posted on our Biobank website, Facebook Page, or Annual Newsletter).

Estimated date (year/month) first Biobank samples/data are needed:

Estimated number of participants needed for entire study project:

Estimated number of participants needed for first distribution of samples (if different from above):

What specific types of biological specimens are desired?

(Check all that apply and complete information in the table for each)

Total number of specimens desired:

Sample(s) requested	Quantity of sample requested (i.e., 3 µg of DNA, 1 vial of cells, etc.)	Number of Participants and Specimens per Participant (if different than above)	Special handling instructions
<input type="checkbox"/> DNA			
<input type="checkbox"/> Serum			
<input type="checkbox"/> Plasma - sodium citrate			
<input type="checkbox"/> Plasma - EDTA			
<input type="checkbox"/> Transformed lymphoblastoid cells			
<input type="checkbox"/> Other tissue (type desired)			
<input type="checkbox"/> Plasma/Serum clinical waste			

Once you have completed the form above, please email it to mitochondrialdb@mayo.edu. A short consultation telephone conversation will then be set up for you to discuss any concerns with Biobank staff. For this meeting, please consider the following information:

1. Will any Biobank samples, data, or data from samples be sent **external** to your Institution (other than data used for scientific publications and data returned to Mayo Clinic)?
If yes
 - a. What will be done?
 - b. How you will ensure confidentiality?
 - c. Will it be posted to a public repository? (i.e., dbGAP)
2. Will you want to match controls to your cases?
If yes, on what factors would you want to match (1st degree relative, ethnicity, sex, age, etc.)?
3. What participant data would you like?
 - a. For instance, do you need demographic data?
 - b. Do you need clinical data from a participant's medical record?

4. Individual research results (IRR's) (information about participants that is discovered as part of the research goals of the study)
 - a. What will they be?
 - b. (When) Will you return the results to the Biobank?
 - c. How will the results be disclosed?
 - d. What personnel do you have (or will be needed) for the collection and return of results?
5. Incidental findings (IF's) (information about participants that is discovered during the course of the research but was not the direct research goal. For example, accidental discovery of chromosomal abnormalities during a GWAS)
 - a. Is your analysis at risk for this type of circumstance?
 - b. If so, what might these be?
 - c. When will you disclose the results to the Biobank?
 - d. How will the results be disclosed?
 - e. What personnel do you have (or will be needed) for the collection and return of results?
6. Has this project been peer reviewed? (*If so, provide reviewer comments*).
7. Sample Aliquots:
 - a. Beyond those discussed above, do you anticipate needing additional aliquots on the same individuals ever again in the future?

What specific assays do you have planned?

What do you plan to do with residual Biobank specimens after your project is complete?