THE MANTON CENTER
for Orphan Disease Research

To request access to samples, complete form and email to gdc@childrens.harvard.edu with subject "Sample Request"

Manton ID# Year of Birth Today's Date

Physician Requesting Sample

Physician Phone Physician Email

Dx/Features if unknown dx

	Yes	No
Does the patient have genetic test results?	☐	☐
Has the patient had a biopsy?	☐	☐

What tissue was biopsied?

What sample are you requesting? ☐ Purified DNA ☐ Tissue (list above) ☐ Other

Other testing performed

Are you requesting funds? ☐ Yes ☐ No

If YES, please complete the "Request Funding Support" form found on our website under "Funding Opportunities"
If NO, please list all sources of funding for your research with the specimens (include name, number and fund period if applicable)

Summary of analysis proposal (please include plan for analysis, methodology, timeline, as well as the person who will be performing the lab work and their contact information):

To be completed by The Manton Center Reviewing Committee

Reviewers' Notes: **Reviewer's Initials**

Status:
- ❑ Accepted with funding terms
- ❑ Accepted with no funding
- ❑ Reason for Rejection
- ❑ Transfer Complete Date

Please initial each of the items below:

_____I understand that if a participant chooses to withdraw from The Manton Center by notifying The Center's research staff, I will be asked to remove that data and sample from further analyses and discard any remaining aliquots of DNA for that participant.

_____I will provide The Manton Center for Orphan Disease Research with any medically relevant results* found, by providing a written summary of findings within 30 days after completing the analysis.

_____I will provide an annual report of genetic analysis data to The Manton Center. Such report will cover all genetic analysis data I have derived prior to the reporting date. These data will be indexed by the Manton ID number assigned at the time of distribution.

_____I understand that pre-publication data will be kept confidential by The Manton Center staff. Pre-publication data, summaries and other "proprietary" research information will remain strictly confidential. Pre-publication data sent to The Manton Center will be tracked in The Center's database and will remain access restricted until published.

_____I will submit any publications to The Manton Center for review before publication, and I will acknowledge The Manton Center in all publications. For example; 'We gratefully acknowledge The Manton Center for Orphan Disease Research at Children's Hospital Boston for providing DNA and/or tissue samples for this study.'

_____I will acknowledge The Manton Center in any and all presentations to the scientific and lay community relating to research on the shared specimens.

_____I will make available, post-publication, any remaining aliquots of specimens that could be useful for further scientific exploration to The Manton Center and other applicants unless an extension of this Agreement is obtained.

_____I will provide The Manton Center with copies of any abstracts and scientific publication relating to research on the shared specimens.

_____ I will comply with NIH guidelines and policies on data and materials sharing with respect to research using these samples.

_____Failure to comply with any of the terms specified herein may result in disqualification of Recipient from receiving additional clinical data, genetic materials, and/or genetic analysis data.

*Medically relevant results are defined as those results where the associated risk for the disease is significant; the disease has important health implications such as premature death or substantial morbidity or has significant reproductive implications; and proven therapeutic or preventive interventions are available as described in Bookman et al.'s (2006) Reporting Genetic Results in Research Studies: Summary and Recommendations of an NHLBI Working Group.

Other Legal terms:

This transfer is for academic or internal non-commercial research only, excluding human subjects research. The specimens provided are NOT identified and are not intended to be identifiable. PI agrees that under no circumstances will PI or any person under his or her supervision attempt to reidentify the samples.

The PI represents that the specimens will be used only in accordance with the terms agreed upon in this document, applicable laws, regulations, grant restrictions, and institutional policies, including without limitation institutional ethical approval, materials storage and handling, staff training, transportation and import/export restrictions. PI and the recipient Institution use the specimens at

solely their own risk, and are solely responsible for all legal compliance, and for obtaining any third-party rights such as any patent or proprietary rights of third parties affecting the proposed research. The PI will notify Children's Hospital immediately if regulatory or institutional approval for the referenced research has been suspended or terminated, and any other incident of substantial noncompliance affecting the continuation of the research.

The specimens are provided as a service to the research community. Children's Hospital makes NO WARRANTIES, EXPRESS OR IMPLIED, AND ALL SUCH WARRANTIES ARE EXPRESSLY DISCLAIMED, EXCEPT WHERE PROHIBITED BY LAW.

PRINCIPAL INVESTIGATOR CERTIFICATION: By signing this form, I certify that the foregoing is true and correct to the best of my knowledge, and that if any part of it becomes untrue to my knowledge, I will communicate to Children's Hospital Boston the changed circumstances.

_____ _____

Signature Date