



Hermansky-Pudlak Syndrome Network, Inc.

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Email: info@hpsnetwork.org Website: www.hpsnetwork.org

Biosample Procurement Consent Form

If you agree to donate blood or saliva specimens, tissue or post-mortem tissue it will be stored for future research purposes. The samples will be preserved indefinitely (or until you withdraw your consent). These samples may be shared with academic and/or industry investigators and used for studies related to HPS.

If you agree to donate tissues following your death, and this is possible without harm to your body or without damage of the tissue, a portion of the post-mortem tissue will be obtained by the study doctor or the study coordinator. This will only be collected in the event of an autopsy performed for standard of care reasons. Because an autopsy is a standard of care procedure, you or your insurance provider will be responsible for the cost of the procedure. Under no circumstance will we ask that you have an autopsy for the collection of tissue for the purpose of research.

I _____, do hereby consent that my blood or tissues may be donated to be used by the Hermansky-Pudlak Syndrome Network, Inc. for the purpose of research. In allowing this, I consent to the transfer of my blood or tissues to be handled by the Biobank as determined by the HPS Network, Inc.

Signature

Date

Witness

Date