

Hermansky-Pudlak Syndrome Network, Inc.

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Lung Explant Consent Form

If you agree, portions of explanted lung tissue or post-mortem lung tissue will be retrieved and stored for future research purposes. If you are scheduled for a lung transplant for standard of care reasons, a portion of the removed (or explanted) lung will be preserved for future research studies. 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 a portion of your lung following your death, and this is possible without harm to your body or without damage of the tissue, a portion of the postmortem lung 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 lung tissue for the purpose of research.

I ______, do hereby consent that my explanted lungs may be used by the Hermansky-Pudlak Syndrome Network, Inc. for the purpose of research. In allowing this, I consent to the transfer of my lung tissues to be handled by Dr. Jon Kropski and sent to the Vanderbilt University Medical Center.

Signature

Date

Witness

Date