Lyme Disease Biobank (LDB) and NDRI Partnership: Human Tissue Collection Program to Accelerate Biomedical Research for Lyme Disease (LD) and other Tick-Borne Infections (TBI)

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Background
Advancing Lyme Disease Research and Discovery: LDB has partnered with NDRI to collect post-mortem and surgical tissue samples from individuals with persistent LD and other TBI. Potential participants will have the option of sharing their information with MyLymeData, leveraging the robust data profiles from MyLymeData with tissue biospecimens. A Tissue Working Group was established to develop collection protocols. This collaborative effort will provide the research community with well annotated tissue biospecimens suitable for state-of-the-art experimental methods that can begin to address key questions surrounding inflammation and infection in tissues from patients with persistent LD.

Lyme Disease Biobank Facilitates LD Research
LDB’s Goal: To provide quality biospecimens to investigators developing improved diagnostics and treatments for LD and other TBI. Currently, samples are available from 435 participants. Each participant’s donation provides samples for ~50 research projects.

NDRI Provides Superior Access to Human Biospecimens
A 501c3 Corporation
NIH Funded for Over 30 Years
6,500 Biospecimens/year to Approved Investigators
~150 Publications Annually

NDRI’s Mission: (1) To advance disease research through the procurement, preservation and distribution of human cells, tissues, and organs (2) to provide researchers with biomedical resources that are essential for their work. NDRI partners with a nationwide network of recovery personnel to serve NDRI’s registered research projects with biospecimens for their studies.

Tissue Working Group Lends Expertise
- Investigators were convened in September 2017 to discuss the tissue collection program, including tissue types and preservation methods.
- A Working Group was established to finalize tissue types, preservation methods, and additional fresh processing for protocol development.

LDB-NDRI Partnership Will Establish a Diverse Collection of Biospecimens for LD and TBI Research
LDB Biospecimens Will Meet the Needs of Investigators

| Biospecimen Collection: Multiple tissue types will be recovered from each donor (Table 1). Brain, heart, and spinal cord will receive additional processing to provide multiple region-specific samples, including frozen aliquots and fixed sections. A neuropathology report will be completed for each brain.

| Biospecimens Annotated with Associated Medical History

Medical History Data:
- Each sample is associated with identified clinical information including medical and social history, laboratory testing results, and LD-specific information (Table 2)
- Medical records will also be obtained when possible.

| Table 1: Post-mortem Frozen and Fixed Tissues

| Table 2: Lyme Disease Specific Medical History Data Collected

| Brain – additional processing will produce multiple aliquots (~11 brain regions including cortex, hippocampus, cerebellum, and brainstem; snap frozen and pulverized aliquots, as well as fixed sections available from each region.

| Heart – additional processing will produce frozen and fixed sections of atria, ventricles, and valves.

| Spinal Cord – additional processing will produce frozen and fixed sections of cervical, thoracic, and lumbar regions.

| Disease burden (employment status)

Biochemistry/Proteomics
Gene Expression
In Situ Hybridization
Histological Analyses

Funding:
Working Group: John Aucott, MD, Johns Hopkins University, Diego Cadavid, MD, Fulcrum Therapeutics, Andrew Dwork, MD, Columbia University, Monica Embers, PhD, Tulane University, Chris Green, MD, Green Oaks Medical Center, Kent Lewandowski, MD, Massachusetts General Hospital

Meeting Attendees: Wendy Adams, MBA, Bay Area Lyme Foundation, Brian Fallon, MD, MPH, Columbia University, Lorraine Johnson, JD, MBA, Lymediseasease.org, Lance Liotta, MD, George Mason University, Working Group Members

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Donation Process: NDRI’s Private Donor Program will maintain a registry of eligible donors, recovering multiple tissues from pre-registered LD donors for the LDB. Potential donors can register online through NDRI’s LDB Private Donor Program (https://ndriresource.org/lyme-disease) or by calling NDRI.

Eligibility Requirements: Potential participants must be 18 years of age or older, reside in the continental US, and be diagnosed with Lyme disease by a healthcare provider. Following initial registration, additional information including medical history, laboratory testing results, and consultation with clinical experts may be part of LDB’s final eligibility determination process.

This collaborative approach between LDB, NDRI, and MyLymeData will yield high quality, well annotated biospecimens suitable for accelerating the development of new diagnostics and treatments for LD and other TBI.

Acknowledgements

Contact Us
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NDRI’s Private Donor Program:
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