

## Poster Presentation for Lyme Disease Association-Columbia Conference 2019



**Liz Horn, PhD, MBI, Principal Investigator, Lyme Disease Biobank** – Liz has spent more than a decade building research initiatives and collaborations with non-profit organizations, with a focus on registries and biobanks. She has been working in Lyme disease since 2013 and was part of the team that launched the Lyme Disease Biobank. The Biobank was created to provide much-needed samples to researchers studying Lyme disease and other tick-borne infections, and each participant's sample donation supports up to 50 different research projects. The Biobank is expanding to collect samples from patients with persistent Lyme disease, including post-mortem tissues.

Liz earned her doctorate in molecular pharmacology and cancer therapeutics from SUNY at Buffalo, was a National Library of Medicine fellow in biomedical informatics, and received her M.B.I. from Oregon Health & Science University. She has mentored and trained >75 advocacy organizations in the translational research enterprise, and helped these groups initiate collaborations with academia, other non-profits, and industry.

### **Lyme Disease Tissue Collection Program – Accelerating Biomedical Research for Lyme Disease and other Tick-Borne Infections**

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The Lyme Disease Biobank (LDB) is partnering with the National Disease Research Interchange (NDRI) to collect post-mortem and surgical tissues from individuals with persistent Lyme disease (LD) and other tick-borne infections (TBI), creating a resource for the research community to study the impact of these infections on the body. This partnership began in 2017 to enable the collection of a diverse range of tissue biospecimens from post-mortem donors, including brain, heart, nervous tissue, musculoskeletal tissue, immune tissue, and other organs. In 2019, we launched an initiative to collect cartilage and synovial tissue from individuals with LD undergoing knee replacement surgeries. This partnership also includes LymeDisease.org, so that participants in the MyLymeData patient registry can link their MyLymeData profile with their tissue samples.

NDRI and LDB use their respective expertise to support the program. NDRI maintains a registry of individuals interested in donating tissues, obtains consent for donation, develops a donation plan, and coordinates the recovery, packaging and shipping of biospecimens to the LDB. LDB determines donor eligibility, manages the processing and storage of biospecimens, and coordinates sample distribution to researchers. This collaboration provides the research community with well annotated tissue biospecimens to further our understanding of how these complex infections invade tissue and accelerates the bench-to-bedside pathway for improved diagnostics and new treatments for patients with LD and other TBI.

This program is provided at no cost to patients and families. Interested individuals can register with NDRI at <https://ndriresource.org/lyme-disease>.

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