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Poster Presentation
Human Tissue Collection
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https://lymebiobank.org/

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 Lyme Disease 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. 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. Her strong foundation in basic science, informatics, registry questionnaire design, governance, and biobank planning and operations makes her well positioned to serve as the Principal Investigator.

2017 Poster Presentation

Lyme Disease Biobank and National Disease Interchange Partnership: Human Tissue Collection Program to Accelerate Biomedical Research for Lyme Disease and other Tick-Borne
Infections

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**Introduction:** The use of human biospecimens provides scientists with a direct experimental model system to advance our understanding of human biology, physiology, disease and other related areas of scientific research. When available, biospecimens play a key role in accelerating bench-to-bedside studies identifying new medical treatment options. The Lyme Disease Biobank (LDB) currently maintains a collection of blood, serum, and urine from individuals with early, acute suspected Lyme disease (LD) and endemic controls. LDB has partnered with the National Disease Research Interchange (NDRI) to expand this collection to include a diverse range of human tissue biospecimens. NDRI has over 35 years of experience serving as a critical link between individuals wishing to donate organs and tissues for research and the nation's leading investigators who are working to find new treatments or cures for a wide range of diseases. NDRI's Donor Programs give patients and their family members an opportunity to make a significant contribution to research and development by providing a straightforward mechanism through which tissues and organs can be donated. The LDB-NDRI partnership will enable the collection of post-mortem and surgical tissue samples from individuals with LD or other tick-borne infections (TBI), providing the research community with a much needed resource to better understand these complex infections.

**Methods:** LDB and NDRI are developing a two pronged approach to accelerate knowledge in LD and TBI:
1) identify patients interested in donating biospecimens for
research and
2) recruit biomedical investigators who can utilize these biospecimens to advance research, diagnostics, and treatment.

During the developmental phase, LDB and NDRI are creating procedures for this program by soliciting feedback from all stakeholders, including clinicians, investigators, and patients and families, to help guide the process. Once the program is launched, NDRI will maintain a registry of individuals interested in donating tissues, obtain consent for donation, develop a donation plan, and coordinate the recovery, packaging and shipping of biospecimens to the LDB for use by approved researchers. To expand the impact of this program, customized recovery protocols will be developed by LDB and NDRI to address the major experimental needs within the Lyme research community. This approach ensures that biospecimens are suitable for the experimental objectives and procedures for numerous investigators, thus greatly amplifying the usefulness and importance of this resource.

**Conclusion:** Together, LDB and NDRI will provide the research community with well annotated tissue biospecimens that are suitable for state-of-the-art experimental methods. Collectively, this approach can play a key role in accelerating the bench-to-bedside pathway to develop improved diagnostics and new treatments for patients with LD and other TBI.

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