



# Lyme Disease Biobank and NDRI Launch Donor Registry to Accelerate Breakthroughs in Diagnosis and Treatment

In the fall of 2018, NDRI and the Lyme Disease Biobank opened a donor registry for the post-mortem recovery of 16 tissue types — including brain, heart and nervous tissue biospecimens — from individuals diagnosed with Lyme disease. The NDRI/Lyme Disease Biobank collaboration will dramatically increase the volume and diversity of well-characterized tissue samples to accelerate medical breakthroughs in the understanding, diagnosis and treatment of Lyme disease and other tick-borne infections.

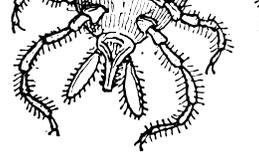
The goal of this partnership is to help more researchers focus

on making Lyme disease easy to diagnose and simple to cure.

The Lyme Disease Biobank is the only national entity collecting surgical and post-mortem tissue samples for research from individuals with persistent Lyme disease and other tick-borne infections. This tissue program builds on the biobank's blood sample collection effort to fuel improved diagnostic tests for Lyme disease. Currently, there are blood samples available from more than 435 participants, and each participant's donation can provide samples for approximately 50 research projects. To date, more than 30 research projects have

used, or are using, samples from the Lyme Disease Biobank.

Because there is no single diagnostic or treatment that works for everyone afflicted with Lyme disease, the Lyme Disease Biobank fills a critical need in providing researchers with the samples they need to better understand the disease and evaluate solutions. One of the most common infectious diseases in the country, Lyme disease is a potentially disabling infection caused by bacteria transmitted to people and pets through the bite of an infected tick. If caught early, most cases can be effectively treated, but Lyme disease is



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“We are thrilled to partner with NDRI and MyLyme Data to create a much-needed tissue repository for researchers studying Lyme disease and working to better understand this complex illness.”

**Liz Horn, PhD, MBI**  
*Lyme Disease Biobank*  
*Principal Investigator*



commonly misdiagnosed due to a lack of awareness and unreliable diagnostic tests. According to the Centers for Disease Control and Prevention there are approximately 30,000 new cases of Lyme disease reported each year and roughly 300,000 people at risk. It can be difficult to diagnose and treat Lyme disease. Approximately, one million Americans may suffer from the impact of its debilitating long-term symptoms and complications, according to Bay Area Lyme Foundation estimates.

This Spring, the partnership between NDRI and the Lyme Disease Biobank will continue to expand with the registration

of surgical donors for tissues associated with knee replacement.

Donors are screened to determine eligibility for donation and acceptance into the registry. Potential donors can also elect to enroll in the MyLymeData Patient Registry, where they can connect their profile with the tissue sample, creating a fuller data set of donors' Lyme disease history and assisting researchers using the tissue samples in discovery. Potential donors can register for the Lyme Disease Biobank online through NDRI's Private Donor Program ([www.ndriresource.org/lyme-disease](http://www.ndriresource.org/lyme-disease)) or by calling NDRI at 800-222-NDRI (6374), Option 5.