About the Lyme Disease Biobank Tissue Program

Lyme Disease Biobank (LDB) Tissue Program aims to accelerate Lyme disease research, and create a greater understanding of the ability of Lyme bacteria to invade tissues and organs. It is the only national entity working to collect surgical and post-mortem tissue samples from individuals with persistent Lyme disease and other tick-borne infections.

People with Lyme disease are invited to register for the LDB Tissue Program by signing up through NDRI (National Disease Research Exchange) and are also encouraged to provide information about symptoms and medical history to our partner MyLymeData. Patients will not incur any specific costs for participating in this program. The LDB Tissue Program offers a critical service to researchers as it is rarely possible to evaluate how tick-borne disease may infect body parts such as a knee joint and even less possible to study vital organs such as a person’s heart and/or brain.

Surgical Tissue Donation

If you are planning to have a surgery that removes tissue from an organ or joint, such as a knee replacement, the discarded tissue can be donated to this research program. Prior to surgery, donors must complete a consent form and eligibility screening.

Legacy Donations

You may be able to help improve research of Lyme disease by making a plan now to donate organs and tissues to the LDB Tissue Program after death from any cause. All patients with Lyme disease are encouraged to register with the program now, and let loved ones know of their decision.

Additional Considerations for Legacy Donations

• Only organs and tissues needed for research will be recovered
• The donation will not prevent you from having a traditional funeral
• NDRI covers all costs associated with coordination of organ and tissue recovery; funeral and cremation costs remain the responsibility of the family decision makers

Eligibility Requirements

• Must be 18 years of age or older
• Reside in the continental US
• Diagnosed with Lyme disease by a healthcare provider
• Provide serology results if available
• Medical history, laboratory results, and other clinical information may be part of the final eligibility determination

> See reverse for more information about our Tissue Program including partnerships and how to register.
National Disease Research Interchange (NDRI), the nation’s leading source of human tissues, cells, and organs for scientific research, partners with LDB for the registration, collection and storage of tissue samples. A non-profit 501(c)(3), NDRI ships thousands of biospecimens annually from our nationwide procurement network to researchers worldwide. NDRI is accredited by the College of American Pathologists (CAP) as a biorepository and a sponsor facility, and meets the standards for human biospecimen collection, storage, informatics, and distribution defined by the CAP Biorepository Accreditation Program. The National Institutes of Health (NIH) has provided funding to NDRI since 1987.

As part of this program, the Lyme Disease Biobank is partnering with MyLymeData to enable the tissue samples to be linked with clinical information, such as symptoms, demographics, medical and social history, and history of Lyme disease and other tick-borne illnesses. More than 12,000 patients have enrolled in the MyLymeData registry, launched by the non-profit LymeDisease.org, which uses big data research tools to confidentially pool patient data to help find a cure. In addition to registering with NDRI, donors are encouraged to enroll in the MyLymeData Patient Registry at MyLymeData.org.

ABOUT BAY AREA LYME FOUNDATION
Bay Area Lyme Foundation is the leading public not-for-profit sponsor of innovative Lyme disease research in the US and a national organization committed to making Lyme disease easy to diagnose and simple to cure. Lyme Disease Biobank (LDB) is a subsidiary of Bay Area Lyme Foundation and is supported by donations from multiple sources including the Steven & Alexandra Cohen Foundation. For more information about Bay Area Lyme Foundation and Lyme disease, visit www.bayarealyme.org or call us at 650-530-2439.

FOR MORE INFORMATION & TO REGISTER
Please complete the form on the right side of the page at ndresource.org/lyme-disease. For more information, call 800-222-NDRI (6374), Option 5.