Transcript from Fifth Annual LymeMind 2020 Virtual Conference

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Today, I'm going to tell you about the Lyme Disease Biobank, a program of Bay Area Lyme Foundation. We created the Biobank to fill a national need to make samples available to researchers working on new diagnostics for Lyme disease. We've enrolled more than 900 participants, and more than 55 research projects are using samples. In 2018, we launched a tissue bank so researchers can study how these infections invade tissues. We're collecting samples from surgeries and samples after someone has passed away. For surgeries, we're focusing on knee and hip replacements and other surgeries on a case-by-case basis. The tissue bank is a partnership with NDRI and MyLymeData, the largest Lyme disease patient registry. NDRI works with patients, families, and medical providers to coordinate the tissue donation. Tissue donors have the option to link their tissue sample with their MyLyme data profile, providing additional information to researchers.

This program is provided at no cost to patients and families. If you're interested in being part of the tissue bank, this is the process. Contact NDRI for more information or to request a registration packet. NDRI sends you a packet including: consent forms to participate, questionnaires about your medical history, and your history of Lyme disease. NDRI will also answer any questions you have. Complete the forms in the packet and return it to NDRI. NDRI sends you a donor registration card confirming your enrollment. If it's a surgical donation, let NDRI know when you schedule surgery so they can coordinate with your healthcare team. If you're planning to donate after you've died, it's important to let your family or next of kin know your wishes. They will need to contact NDRI to coordinate the donation. The samples are then sent to the Biobank, and we make them available to researchers.

Know that you are making a difference and your donation makes research possible. Please visit our website for more information. We would like to thank the participants who donated samples, our partners, and our funders, Bay Area Lyme Foundation, the Steven and Alexandra Cohen Foundation, and an anonymous donor. Thank you very much.