



Emily Erbelding, MD, MPH, Director
Division of Microbiology and Infectious Diseases
National Institutes of Health (NIH)
9000 Rockville Pike
Bethesda, Maryland 20892

Dear Dr. Erbelding,

We appreciate your response to our July 9, 2020 letter. However, we are disappointed that you do not address our concerns and our specific request for NIH to make research on congenital and pediatric Lyme disease a priority.

Your response states that NICHD “welcomes grant applications for research that would address questions related to congenital and perinatal infections, including Lyme disease.”

This is insufficient. **We want NICHD to designate Lyme disease as a high-priority perinatal infection of interest**, as it does for other congenital infections, under the NICHD notice, “Advancing the Understanding, Prevention, and Management of Infections Transmitted from Women to their Infants.”

If you believe that Lyme disease does not merit this designation, we’d like to know why, and what additional information, or actions, are needed to make it a priority.

We are familiar with the NIAID Strategic Plan for Tick-Borne Diseases, and the Notice of Special Interest for Advancing Research for Tickborne Diseases. Neither of these publications addresses the need for research on maternal-fetal transmission of Lyme disease or other tickborne diseases.

We also appreciate your statement that “NIH encourages inclusion of children, women, and minorities in clinical research as much as possible, and reviewers are asked to specifically look for inclusion of these special populations in clinical research applications as an integral part of the dual-level peer-review process.” However, NIAID’s recently updated report, Current Efforts in Lyme Disease Research, makes no mention of any of these special populations.

We would like to call your attention to the following report language for NIH’s FY 2021 appropriations that was recently passed by the House Appropriations Committee.

“Maternal-Fetal Transmission of Lyme Disease. —The HHS Tick Borne Disease Working Group’s Clinical Aspects of Lyme Disease Subcommittee January 2020 report includes “further evaluate potential maternal-fetal transmission of Lyme disease and of congenital Lyme disease” as a recommended priority. The Committee urges NIH to evaluate potential

maternal-fetal transmission of Lyme disease and congenital Lyme disease and issue requests for proposals and funding opportunity announcements to stimulate researcher interest in these areas. Within 180 days of enactment of this Act, the Committee requests a report on NIH plans to address the need for research on maternal-fetal transmission of B. burgdorferi, congenital Lyme disease, and adverse outcomes in infants and children from maternal transmission.”

The letter that submitted this language was signed by 16 members of the House Lyme Caucus, including the chairwoman of the Energy and Commerce Subcommittee on Health.

Additionally, a December 2019 letter from seven U.S. Senators to Dr. Fauci posed the question, “What research is the agency planning to conduct or incentivize to improve understanding of modes of transmission, including vertical transmission?”

Dr. Fauci responded:

“Further exploration into non-vectored transmission of B. burgdorferi, such as sexual or vertical transmission, is needed to conclusively identify these routes as contributing to Lyme disease burden. However, adverse birth outcomes among women with untreated and disseminated Lyme disease during pregnancy have been shown”

Both your response to our letter, and Dr. Fauci’s response to the Senate letter, acknowledge vertical transmission of Lyme disease. We want you to take it a step further and **make this research a priority.**

We would like to continue our discussion with NIAID and NICHD and understand how our organization can work with NIH to make this research happen.

We look forward to your response.

Respectfully,

Mothers Against Lyme



Isabel Rose, *Chairman of the Board*
Isabel.Rose@MothersAgainstLyme.org