



Francis S. Collins, M.D., Ph.D., Director
National Institutes of Health (NIH)
9000 Rockville Pike
Bethesda, Maryland 20892

July 9, 2020

Dear Director Collins,

As mothers who have experienced firsthand the devastating impact of misdiagnosed and untreated Lyme disease on our children and families, we urge you to support research that will prevent other families from suffering as ours have.

We and our children have had to overcome the challenges of misdiagnoses, delayed care, obstacles to treatment, and the financial burden of out-of-pocket expenses. Our family life has been forever changed; our careers have been interrupted; and our children have lost key years and experiences they will never regain.

Many of our children have missed months to years of school; some have required specialized education; others residential treatment. Our children, their siblings, our family life—all have suffered.

We need your attention.

We are aware that the HHS Tick-Borne Disease Working Group has recognized pregnant women and children as special populations who suffer disproportionately from tick-borne diseases. We know The Working Group now notes that gestational Lyme disease can cause premature labor and fetal death. We are also aware that that CDC has updated its literature and website to recognize maternal-fetal transmission of Lyme disease.

This should mark the beginning only of the NIH's mandate to study the needs of these women and children.

Research is urgently needed on the risks of maternal-fetal transmission of Lyme disease and its diagnosis and treatment in pregnant women and any babies born with tick-borne illnesses.

Pediatric Lyme disease from any mode of transmission deserves similar attention. When Lyme disease goes undiagnosed and untreated in a child, the physical health, mental health, and capacity to learn are severely compromised, adversely affecting their entire life trajectory.

Many of our children with Lyme disease have neurological involvement with symptoms that have not been well-described or well-studied, leaving doctors perplexed.

We believe that our children suffer disproportionately from illnesses such as Attention Deficit Hyperactivity Disorder, Obsessive-Compulsive Disorder, Depression, Bipolar Disorder, Anxiety Disorders (separation anxiety, panic disorder, dissociative disorders), and Autism Spectrum Disorder.

To address these concerns, we urge NIH to make research on the impact of Lyme disease on pregnant women and children a high priority.

Objectives are to:

- improve prevention, diagnosis, testing, and treatment of Lyme disease and discover other tick-borne diseases in pregnant women, infants, and children
- determine the extent of maternal-fetal transmission and investigate the impact of congenital Lyme disease
- establish best practices for prevention and treatment of maternal-fetal transmission and congenital Lyme disease
- understand the social, educational, cognitive, psychological, behavioral, and life outcomes for children infected with Lyme disease
- increase awareness of common symptom presentations among obstetricians and pediatricians.

To achieve these goals, we ask NIH to incorporate input from parents of children with Lyme disease when setting research priorities.

We also request that patients, advocates, and physicians with experience treating tick-borne diseases be included as representatives on the Advisory Board/Councils that review grant applications for this research.

In order to reach these goals, research needs studies that:

- assess birth outcomes and monitor growth and development in babies born to mothers with acute, previously treated or late disseminated Lyme disease.
- determine the appropriate antibiotic regimen to prevent transmission of Lyme disease from mother to fetus.
- examine the effects of pregnancy on immune response and symptoms.
- assess the immunological response in children who are congenitally infected with Lyme disease.
- evaluate the role co-infections play in the diagnosis and treatment of Lyme disease in pregnant women and in children who may have acquired Lyme disease in utero or through tick bites.

We also ask NIH to authorize longitudinal studies on the risks of developmental disorders and other long-term impacts of untreated or insufficiently treated Lyme disease in children.

These must address:

- Social, educational, cognitive, psychological, behavioral, and life outcomes for children infected with Lyme disease in utero or in childhood.
- Common neuro-psychiatric presentations of congenital and primary Lyme disease in children.
- Educational needs of children affected with Lyme disease, with recommendations for school accommodations that allow for treatment of neuropsychiatric and physical disease.

The mission of the National Institute of Child Health and Human Development (NICHD) is to: “lead research and training to understand human development, improve reproductive health.”

Given this mission, we ask NICHD to add Lyme disease to its list of high-priority perinatal infections of interest. The notice of special interest “NOT-HD-19-021: Advancing the Understanding, Prevention, and Management of Infections Transmitted from Women to their Infants,” released in September 2019, is the perfect umbrella for these studies.

Mothers, children, and families whose lives have been disrupted by the devastating effects of Lyme disease are counting on NIH to provide solutions by making this a high priority, and by supporting scientific research and evidence-based policy.

We would appreciate a timely response to our requested actions and a summary of NIH’s plans to conduct research on congenital and pediatric Lyme disease.

Respectfully,

Mothers Against Lyme



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

With agreement of Mothers Against Lyme ad hoc committee:

Holly Ahern¹, Kristina Bauer², Sue Faber, RN³, Chris Fisk¹, Bruce Fries⁴, Susan Green⁵, Mira Shapiro, Monte Skall⁵, Monica White⁶, Ronald Wilson, MD,⁷ Rosalie Greenberg,⁸ MD, Jane Marke, MD⁸

¹ Lyme Action Network, ² Texas Lyme Alliance, ³ LymeHope, ⁴ Patient Centered Care Advocacy Group, ⁵ National Capital Lyme and Tick-Borne Disease Association, ⁶ Colorado Tick-Borne Disease Awareness Association, ⁷ International Lyme and Associated Diseases Education Foundation, ⁸ Private Practice, Psychiatry