

## **Treat Now, Research Always: A Call to Action for Those Living with Lyme infection-Associated Chronic Illnesses**

*By The International Lyme and Associated Diseases Society (ILADS)*

Tens of thousands of Americans develop persistent, life-altering symptoms each year after contracting Lyme disease - a condition now recognized by the National Academies of Sciences, Engineering, and Medicine as **Lyme Infection-Associated Chronic Illness** (Lyme IACI). A new consensus report, *Charting a Path Toward New Treatments for Lyme Infection-Associated Chronic Illnesses*, calls for urgent attention to these patients, citing the lack of effective treatments, diagnostic tools, and coordinated research. The International Lyme and Associated Diseases Society (ILADS) welcomes this report as a crucial step forward. But we urge the medical and research communities to act on one essential principle: **patients cannot afford to wait for perfect science to receive compassionate care.**

The National Academies report rightly identifies that many people with Lyme IACI experience disabling fatigue, pain, cognitive dysfunction, and sleep disturbances - symptoms strikingly similar to those found in Long COVID and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Yet unlike these conditions, where progress toward treatment development is accelerating, patients with Lyme IACI still face stigma, dismissal, and inconsistent care. Often, the most stigmatized symptoms suffered by patients are neuropsychiatric and debilitating.

### **What Patients Need Now: Compassionate, Evidence-Informed Treatment**

While some may interpret the report's conclusion - that no treatment has yet demonstrated sustained benefit in randomized clinical trials - as a reason to withhold care, ILADS strongly disagrees. The absence of large-scale, definitive trials does not mean there are no effective treatments - only that the research hasn't caught up to clinical reality.

In medicine, we often treat conditions without a complete understanding of their mechanisms. In alignment with Recommendation 1 - Research funders should prioritize improving the function and quality of life for people living with Lyme infection-associated chronic illnesses, including the relief of common symptoms, with scientifically supported interventions.

To ensure these interventions are supported by robust evidence, clinical studies should be well-designed, randomized trials with appropriate control groups and, whenever possible, include collection of data to help further understanding of disease mechanisms.

Lyme IACI should be no different. The ILADS approach supports the use of **individualized, patient-centered care based on clinical judgment, biological plausibility, and patient-reported outcomes**. In the real world, many patients improve with tailored therapies, including antimicrobial, immune-modulating and symptom-targeted treatments - especially when these treatments are guided by an experienced clinician who listens to the patient and tracks outcomes over time.

### **Standardization Can Help, But It Must Not Delay Care**

The report rightly calls for standardized definitions, outcome measures, and research tools. These are essential for advancing science. But we caution against using the absence of consensus as a reason to exclude patients from diagnosis or deny treatment. Conditions like Long COVID and ME/CFS have made progress because their definitions embraced the heterogeneity of illness and included patient input. Lyme IACI deserves the same respect.

### **Research and Treatment Must Move in Parallel**

There is no doubt that we need better diagnostics, larger biobanks, AI-supported data analysis, and robust clinical trials. But let's be clear: **research takes years**. Patients suffering today do not have time to wait. We must follow a dual-path strategy: invest in long-term research, while also expanding access to care based on current best practices. This includes treatments with emerging or empirical evidence that have shown benefit in some patient populations and carry an acceptable risk profile when monitored responsibly.

The research community and other governing bodies of medicine want consensus, randomized controlled trials, and clarity around disease mechanisms and new and repurposed treatments. We agree. This requires a large commitment to funding by the biggest single entity in the world, the US National Institutes of Health. A division of research for IACI would accomplish this overdue emphasis on understanding the varied human response to infectious diseases and microbiota alterations that can indeed lead to chronic illness and suffering. At the NASEM meeting, the organizers cited the movement among patients and advocacy groups that led to robust funding for people impacted by HIV, which in turn led to the development of therapies and even preventatives for a once-fatal disease.

The cumulative impact of ALL microbial infections in the onset and progression of chronic disease is presently unquantified, and this also needs to change.

### **A Unified Vision with Patients at the Center**

The National Academies report calls for a unified research agenda across infection-associated chronic illnesses (IACI), including Lyme, Long COVID, and ME/CFS. ILADS agrees - but such efforts must be informed by those with lived experience. We cannot afford to repeat past mistakes of sidelining patient voices or limiting treatment access due to rigid academic debates. Progress depends on **co-creation**, not top-down mandates. Several treatment strategies already exist within the clinical setting. As the leading medical society serving this community, ILADS historically has been at the forefront of caring for patients with complex pathophysiology. Such care requires a personalized, individualized plan of care.

### **The Ethical Imperative: Treat While We Learn**

At ILADS, we believe there is an ethical obligation to relieve suffering, even amid scientific uncertainty. For patients with Lyme IACI, dismissing symptoms or delaying treatment until a gold-standard trial is published is not only unhelpful - it's harmful. Medicine must remain both a science and an art, grounded in evidence and guided by empathy.

The time for action is now. Let's support robust, coordinated research. But let's also empower clinicians to treat - responsibly, compassionately, and without fear. Because when it comes to Lyme IACI, patients need more than promises of future solutions. **They need help today.**

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### **About ILADS**

The International Lyme and Associated Diseases Society is a nonprofit, multidisciplinary medical society dedicated to the appropriate diagnosis and treatment of Lyme and associated tick-borne illnesses. ILADS promotes patient-centered, evidence-informed care and supports research that advances understanding of persistent Lyme disease.

A few ILADS Stats:

- ILADS is the **ONLY** nonprofit membership organization representing programs and professionals worldwide that focuses on Lyme Disease and Vector-Borne illnesses.
- We are a unique community of some 570 members across the United States and the world who represent allopathic and naturopathic training. Our members strive for individualized, comprehensive patient care, looking at the whole patient and seeking

excellence in their standard of care. ILADS members include physicians, scientists, researchers, and other healthcare professionals,

- [ILADS 2024 Impact Report](#) showcases several stats, including: our [ILADS Provider Search](#) is accessed over 37,000 times a year by patients, advocates and clinicians seeking the best care.
- We recognize the pivotal role of education in the medical community. Our ultimate goal is for healthcare professionals to leverage this information to make a positive impact on their patients' lives.
- We have signature educational offerings including courses on tick-borne illness, shadowing opportunities and a host of in-person and on-demand content.