



Cutting-Edge Science Gives Hope to the Lyme Disease Community

The Johns Hopkins Lyme Disease Research Center was featured in a five part NBC News series, “Lyme Wars”, that aired mid-October 2017. NBC reporter, Erica Byfield, interviewed John Aucott, MD, Johns Hopkins Associate Professor of Medicine and Director of the Center, and Mark Soloski, PhD, Johns Hopkins Professor of Medicine and Co-Director for Basic Science. In Part III of the educational series titled [“How Scientists Are Working to Understand Lyme Disease”](#) they discussed the importance of the Center’s research, including their focus on developing better Lyme disease diagnostics and improving the understanding of the complex biologic causes that drive persistent symptoms. Over 40,000 blood samples have been collected from Lyme disease patients at the Center and are being stored in freezers to be used in ongoing research studies. These precious blood samples are vital to research and could possibly be a key to a cure.

The diagnostic tests for Lyme disease definitely need to be improved. Current diagnostic tests are antibody-based and look for the immune response to the bacteria and do not detect the infectious bacteria directly like a culture of DNA PCR test would. Having a direct test would enable improved accuracy and facilitate the monitoring of treatment success which is currently lacking with present antibody-based testing. Research at the Center focuses on the potential roles of immune dysfunction as well as bacterial persistence and other biologic mechanisms in causing ongoing symptoms. Some symptoms could be driven by an inappropriate immune reaction to infection. Dr. Soloski finds this intriguing because there are treatment approaches that could control such respons-

es. Dr. Aucott adds, “If we understood the causes of lingering symptoms much of the [Lyme Wars] debate would go away. It would also go away with better testing, also a focus of the Center. The diagnostic tests for Lyme disease definitely need to be improved”.

The Johns Hopkins Lyme Disease Research Center is a national leader in the search for solutions to the Lyme disease epidemic. The Center promotes research leading to the improved understanding of Lyme disease and its varied manifestations and focuses on translating research into clinical practice. The Center’s research strives for more accurate diagnosis and more effective treatments to improve outcomes and bring renewed hope to Lyme disease patients and their families.

Case Study Published on “Early Disseminated Lyme Disease with Carditis Complicated by PTLDS”

[Our case study](#) reviews one of the first reported cases of Post-Treatment Lyme Disease Syndrome (PTLDS) following Lyme carditis. The patient’s carditis was well documented with a presentation of heart block that resolved quickly after the administration of appropriate antibiotics. However, her diagnosis was delayed due to mischaracterization of her initial rash as a drug reaction instead of *erythema migrans* and her flu-like symptoms erroneously attributed to a viral illness instead of Lyme disease. Lab results were also initially misinterpreted and seasonal and geographic clues in the presenting history were overlooked as well. Since Lyme disease is highly endemic in the Northeast and Mid-Atlantic, particularly in summer months, travel history is an important diagnostic consideration (Rural Maryland in

early June and a history of tick bites were disregarded clues).

Lab tests eventually came back positive for Lyme disease and Lyme carditis was diagnosed.

The development of carditis is hypothesized to be a risk factor for PTLDS because it ensues during the disseminated phase of infection, which is more likely to occur when there is a delay in diagnosis. This expectation is consistent with other recently reported cases of carditis, in which a delay in diagnosis resulted in death.

Although the patient’s carditis resolved with antibiotic therapy many symptoms persisted and were characterized as PTLDS. Risk factors for PTLDS include greater severity of initial disease prior to treatment of Lyme disease, delay in diagnosis, and the presence of neurologic manifestations. This patient had all these contributing risk factors.

This study reveals the severity of illness that can result from delayed diagnosis and misdiagnosis of Lyme disease. Lyme carditis is potentially fatal and PTLDS can cause significant decline in quality of life and daily functioning.

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Lyme disease spirochetes infecting heart tissue

Improving the understanding, diagnosis and care of patients with persistent symptoms due to Lyme disease

Lyme Disease Expanding Geographically

Lyme disease is an expanding epidemic and is now hyper-endemic in the north-eastern and mid-Atlantic US, the upper Great Lakes region and regions of the Pacific Northwest including northern California. Lyme disease is also spreading across Canada, Europe, and Asia. The ticks that transmit Lyme disease have now been [found in half of all US counties](#) including [56 of the 58 counties in California](#). Expansion has been progressive year-by-year, and greater numbers of people and regions of the United States are being exposed to Lyme disease every year. Incidence of Lyme disease in the US is over 300,000 annually, exceeding breast cancer and HIV/AIDS combined.

In the northeastern and mid-Atlantic US and the upper Great Lakes region, acute cases of Lyme disease are more prevalent in the spring and early summer months and again in the fall. In places such as northern California, with more temperate year-round climates, however, acute Lyme disease is a year-round problem. Lyme disease is one of the [climate change indicators the EPA follows](#) when tracking global warming. Ticks can bite people when temperatures exceed 40 degrees regardless of the season. If temperatures are mild, even New Englanders are not safe in the winter. Warmer temperatures enhance the ability of ticks and their hosts to survive in broader geographic locations. As global warming continues, Lyme disease will not only continue to [expand geographically](#) but the risk will [expand seasonally](#) as well.

Successful First Lyme Disease CME Course

The Johns Hopkins Lyme Disease Research Center offered its first Continuing Medical Education (CME) course in June 2017. The course was well received and was attended by over 100 general practitioners, family practitioners, nurse practitioners and student trainees. Physician education on Lyme disease is needed to more adequately address the burgeoning

epidemic of over 300,000 new cases per year in the US. Delayed diagnosis and misdiagnosis are a problem and to improve patient care healthcare providers need to advance their understanding of the complexities of the illness.

The diagnosis of all manifestations of Lyme disease and Post-Treatment Lyme Disease Syndrome (PTLDS) in the clinical practice of medicine is challenging. Timely diagnosis of acute Lyme disease can be improved by more accurate identification of the early *erythema migrans* skin lesion, which may or may not always be present or recognized. Untreated, Lyme disease can progress to disseminated infection involving the nervous system, heart and joints. Early antibiotic treatment of Lyme disease is usually effective in resolving the objective manifestations of infection. However, a subset of patients experience post-treatment persistent symptoms called Post-Treatment Lyme Disease Syndrome (PTLDS). Experts from the Center have carefully described the symptoms, physical findings and laboratory results in a well-documented study of patients with PTLDS.



Our CME course provides education on the spectrum of illness associated with Lyme disease and PTLDS. Our course teaches health practitioners how to:

1. Identify the many different appearances of the *erythema migrans* rash of Lyme disease
2. Describe the limitations and strengths of current criteria and tests used for the diagnosis of the different stages of Lyme disease
3. Compare and contrast the symptoms, signs and natural history of untreated Lyme disease to those of Post-Treatment Lyme Disease Syndrome

4. Identify the challenges to the diagnosis and treatment of Post-Treatment Lyme disease Syndrome

The Center plans to offer another CME course for health care providers again in the spring of 2018.

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