

Chronic Lyme Disease and Associated Co-infection Research

Presentation to the Institute of Medicine of the National Academies
By The National Capital Lyme & Tick-Borne Disease Association

April 29, 2010

This afternoon we have heard some very important and impressive presentations. But they were presentations that were sterile scientific discussion. We must not forget that this scientific inquiry is motivated by the human experience of a devastating disease. It must continue to be motivated by that human experience as long as that motivation does not prejudice the scientific method.

Lyme disease patients face tremendous suffering and disability. One study found that chronic Lyme patients experience the quality of life of someone with congestive heart failure or osteoarthritis and suffer more impairment than someone living with type II diabetes or a recent heart attack.¹ Despite the assertions of some researchers that we have the answers that we need, there is much to do in the area of Lyme research. There are many theories that have been studied, recommended further research and that deserve support to conclude their potential validity. As the Canadian Broadcasting Corporation (“CBC”) radio program: *Ideas: The Bacteria Revolution* reported over a decade ago: “Sorting out all the various symptoms caused by tick-borne diseases is no picnic, and both the detection and the treatment of Lyme are surrounded by controversy.”²

Lyme disease patients are sick – sick of having their real life experience disclaimed as “anecdotal.” Researchers at Columbia University in New York City published a study in 2008 that added that the fatigue level in chronic Lyme disease patients is equal to that of multiple sclerosis.³ Other studies have described the fatigue as “profound, notable, unusual, debilitating, and extreme, not as a vague symptom of tiredness.”⁴ Two earlier articles in the *Annals of Internal Medicine* attributed “long-term impairment of functional status”⁵ to exposure to Lyme disease.⁶ Two more researchers concluded that “some patients with LB [Lyme borreliosis] have fatigue, musculoskeletal pain, and neurocognitive difficulties that may last for years despite antibiotic treatment. The prevalence of symptoms was significantly higher in the LB patients.”⁷ Studies suggested that Lyme disease can trigger fibromyalgia,^{7,8,9} which now afflicts close to two percent of the United States population.¹⁰ Science has repeatedly suggested a connection between Lyme infections and deadly neurodegenerative conditions such as multiple sclerosis,^{11,12,13,14,15} lupus,¹⁶ Lou Gehrig’s disease,^{17,18,19} Parkinson’s,^{20,21,22} recurrent meningitis^{23,24} and schizophrenia.^{25,26} A 2004 article in the *Journal of Alzheimer’s Disease* stated that “Borrelia antigens and genes were co-localized with beta-amyloid deposits in these AD cases. They suggest that these spirochetes, perhaps in an analogous fashion to *Treponema pallidum* [the causative agent of syphilis], may contribute to dementia, cortical atrophy and amyloid deposition.”²⁷

Columbia University’s Chronic Lyme Research Center has probed a possible connection between Lyme and some cases of autism²⁸. *Medical Hypotheses* recently published a paper noting the geographic and symptom overlaps between Lyme and autism, among other factors.²⁹ Concerned parents have started the Lyme-Induced Autism Foundation, which sponsors annual conferences on the topic.³⁰ Considering that CDC statistics show that boys aged 5-9 are at

highest risk for Lyme³¹ and that autism incidence clusters among young boys,³² the Lyme-autism connection deserves investigation.

While the establishment medical community clings to the idea that Lyme disease is easily diagnosed and cured, many physicians in the clinical trenches are convinced that many patients are difficult to diagnose and there may be no way of curing this infection with currently available methods.

That we need more and better research is obvious! Indeed, as the forgoing summary indicates, there are many researchers, and many more potential researchers interested in exploring the unknown regions of Lyme disease. We need to attack this problem seriously and systematically. We will not take your time to detail further the tragedy that Lyme and associated tick-borne diseases can visit upon their victims. Others here will surely provide you with that information and it has, unfortunately, become plentiful in the literature and the blogosphere. We commend that reading to you as it will inform you about the so-called “anecdotal” evidence that we are dealing with a disease crisis in the United States that is growing in exponential proportions and that is so devastating that it takes will to live from its victims. We ask that you move beyond the same researchers who have received the lion’s share of tick-borne disease funding in the past and reach out to new researchers, willing to think outside the traditional box or who might come up with entirely new boxes of scientific inquiry.

As the CDC program I referred to earlier reported: it is fascinating how quickly conventional thinking about diseases can change. Pointing to Amherst College biologist Paul Ewald’s discussion about the complete about-face in the medical community over what causes ulcers. As you are all now aware, every medical text from the 1970s listed nearly everything as a cause of ulcers *except* infection. It took Barry Marshal – using a very unconventional method -- to prove *Helicobacter pylori* as cause of ulcers. That unconventional method resulted in a Nobel prize.

There are many interesting and useful proposals that are in need of recognition and funding. We are fortunate to have two here in the National Capital Area that we would like to bring to your attention.

Dr. Ahmed Kilani, Ph.D. of Clogen Labs in Germantown Maryland believes there is a definite genetic component relating to how different individuals react to Lyme disease and that could explain why some have mild slow progressing symptoms and some lose mobility and become disabled despite treatment with antibiotics and supplements.

He believes that the sensitivity of diagnostic assays for Lyme disease that are commercially available today remains questionable. For example, PCR detection of the spirochete DNA can result in false negative results in chronically ill patients if whole blood is tested because the spirochete prefers to hide in tissues. There are difficulties with biopsies and western blot detection that can also be misleading because there are patients with confirmed Lyme infections that fail to produce any specific bands on the western blots for both IgG and IgM.

Therefore, the need for a more sensitive diagnostic assay is urgent. He believes a starting point could be a study of gene regulation in animal models challenged with *Borrelia*. This proposal suggests the use of Microarrays to study gene regulation during different phases of infection in

mice. The goal of his study would be to define a set of genes whose expression consistently changes in Lyme infections and to use that pool of genes as a diagnostic indicator for Lyme disease.

Dr. Samuel Shor is a practicing physician in Northern Virginia and Associate Clinical Professor of Health Care Sciences at George Washington University, where he has taught since 1991. Dr. Shor has studied chronic fatigue syndrome and published several articles on the subject.³³ Lately, he has been studying the link between tick-borne diseases and the symptoms of chronic fatigue syndrome. Dr. Shor has developed a study proposal to examine this relationship and is seeking a study sponsor.

Both Doctors Shor and Kilani seek new approaches to diagnosing chronic Lyme sufferers so that they may receive proper treatment for the actual ailment they have. Both of them are breaking new ground in the battle against infectious, chronic disease and would be an asset to your panels in the fall.

In conclusion, research has implicated Lyme disease as the cause, or at least the imitator, of many serious medical conditions. We need definitive studies to identify Lyme disease so it can be effectively diagnosed and treated. Given the failure of traditional medical approaches in identifying long-term Lyme syndrome, it is time for a new approach to identify, once and for all, a reliable and accurate test for Lyme disease. Patients suffering with idiopathic conditions ranging from chronic fatigue syndrome to Alzheimer's disease deserve to know whether or not their medical conditions ultimately spring from an undiagnosed and untreated Lyme infection.

Great complexity and seriousness surround the issue of post-treatment Lyme disease symptoms. The Lyme patient community has often been portrayed as seeking only more antibiotics in a fruitless quest for symptom relief. Given the plethora of evidence that the Lyme organism is a formidable and resistant foe to immunity and antibiotics alike, it would be more appropriate to ask for more research into Lyme's properties and possible treatments. New and open minds need to address this frightening and spreading epidemic with humility, flexibility, and a willingness to follow the evidence wherever it leads. In this regard, the panel would be well served with the contributions of Doctors Shor and Kilani.

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