

Bonhomme, Penny

From: Tim Lamb [timlamb@constadv.com]

Sent: Tuesday, March 06, 2012 4:43 PM

To: PHC Testimony

Subject: LYME DISEASE PUBLIC HEALTH HEARING

Madame Chairwomen & Representatives on our Public Health Committee:

I consider myself to be open and objective but I come at this from the side of a parent whose child has experienced and is experiencing the "Lyme Controversy" first hand. The legislature should be made aware there is a controversy in both the diagnosis and treatment of this and other Tick Borne diseases.

I believe an objective person will realize there are problems or there would not be such a major controversy. The controversy ranges from the duration of the tick attachment, the diagnosis and then the treatment of Lyme and Tick Borne Diseases.

One item which can't be overlooked is the tick population is growing and the risk of exposure is significant whether one goes by Dr. Kirby Stafford's statistics from the State Department of Entomology, 32% of ticks tested in 2010 were positive for Lyme borreliosis or Dr. Eva Sapi of the University of New Haven's random sample from 6 Fairfield county towns in 2008 / 2009 where up to 92% of ticks tested were positive for Lyme borreliosis (88% to 92% depending on the town) or a different study by Columbia University researchers finding ticks collected in Westchester County where 65% were infected with the Lyme borreliosis.

Lyme disease is being infected by a spirochete bacteria named borrelia burgdorferi. Syphilis is another well-known spirochete bacteria. Ticks also carry Babesia parasites (similar to malaria in infecting red blood cells), Bartonella henselae (cat scratch fever), Ehrlichiosis, mycoplasmas and other various pathogens. I have met a few parents where the children have co infections which don't show up on the serological testing until months into treatment.

"The task force shall consist of two members experienced in the study of infectious disease" and I assume this to mean two members of the Infectious Disease Society of America, "IDSA". While I understand experts are required, including members of the IDSA one should understand there is a risk in this approach. I believe most members of the IDSA may have an inherent bias. I say this but would like to point out three items that influence my belief.

First of course is our own experience with the "top Lyme" Pediatric Infectious Disease MD at Hartford Children's Hospital.

Our daughter had been ill for 8+ months, had seen 9 MD's, 2 Children's Hospital's (Hartford and Boston), numerous tests, before we started to learn about the controversy. During this 8 month period 4 months was under the care of the top Pediatric Infectious Disease MD at Hartford Children's Hospital who at our last appointment stated "I know Lyme and your daughter doesn't have Lyme Disease". He was steadfast in keeping with his first diagnosis and by this time we couldn't understand why he ruled out Lyme when her medical issues started 3 weeks after we removed a tick. He of course lost her to follow up, like so many other patients I'm sure (I have met the parents of 3 other children where he gave the same diagnosis "streptococcal infection resulting in chronic fatigue syndrome" in the waiting room of one of our daughters Lyme literate physicians). I'm sure he believes our daughter was cured and doesn't even realize when he

turned to me at her last appointment and said some of these symptoms are and then twirled his finger around his temple to indicate psychosomatic.

Second is from my research in the development of the diagnosis of Lyme disease guidelines. The Lyme Committee of the IDSA in 2000, when it was establishing diagnosis and treatment guidelines, dismissed one member of the committee and the Chair subsequently resigned. With these two members off the Lyme committee there was unanimous approval of the diagnosis and treatment guidelines. The guidelines included the Center for Disease Control standard on diagnosis. Senator Richard Blumenthal, then our Attorney General, challenged these guidelines when they were updated in 2006. The IDSA was able to develop a compromise where they had a separate committee comprised of IDSA members review the process and procedures utilized by the Lyme committee and validate the process and procedures. Unfortunately the underlying research used in the processes was not reviewed but that is a separate issue. The same members on the committee in 2000 are on the committee today.

Three is from reports of medical professionals who have treated patients with longer course medications and have been challenged and prosecuted by Insurer's and State Medical Boards. It is difficult to find a medical professional who will treat a patient with long term medications and run up against the medical profession who insists on following the IDSA guidelines. I believe you may find this with professional members you try and recruit to this project.

The profession insists on "evidence" based medicine but allows the Lyme committee of the IDSA conclusions to dictate diagnosis and treatment and allows the Lyme committee to ignore research which produces evidence conflicting with its findings.

The controversy has its beginnings when Polly Murray of Lyme, Connecticut first brought the findings of 37 children diagnosed with Juvenile Arthritis to the Connecticut Health Department in October of 1975. The subsequent research done by Alan Steere from his "enlarging clinical spectrum" published in the Annals of Internal Medicine in 1977 to his Western Blot (a serological test) work with antigen band 41 as being important (both in 1986 and 1988 papers) in confirming clinical diagnosis to his 1993 paper on the Over Diagnosis and Over Treatment of Lyme Disease. This latter paper resulted in the Centers for Disease Control adopting the two tiered serological testing approach with an Elisa screening test and then a Western Blot following Engstrom for the IgM and Dressler (including Alan Steere as a co-author) for the IgG (actually the Dressler paper was for both the IgM and the IgG but Engstrom's was more restrictive, i.e. less Lyme borrelia specific bands).

We have gone from "perceived" over diagnosis and over treatment to actual under diagnosis and under treatment.

The IDSA adopted this two tier serological approach but if one actually reads the research papers they will see each method had a high incidence of false negatives (Engstrom's IgM - 11 of 55 or 20% and this is what is used today). In 2008, 14 years after the standard was established Dr. Alan Steere published a study supporting the two tiered approach but if one actually reads the study they will see all the participants without an EM rash had to pass the Elisa and Western Blot two tier test to be considered for the study.

This is what is known as a Catch 22 scenario the patients had to pass the tests to be considered to have Lyme disease to qualify and then only those qualified are tested.

It's amazing there is a controversy to this insidious disease and I've found it easiest to show a couple of u tube video's on the controversy.

http://www.youtube.com/watch?v=PVPRWiukp_M

<http://www.youtube.com/watch?v=8yk0C-uX9cU>

If you watch this video you can see some of the miss diagnosis.

<http://www.youtube.com/watch?v=3nlulF6q8FA&feature=related>

<http://www.youtube.com/watch?v=V-IHDA863TM&feature=related>

Unfortunately my daughter is not the only child mis-diagnosed and mis-treated due to the current guidelines.

Thank you for your time,

Tim

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