

Part 20:

Who gets to decide when doctors are divided?

The medical field in the U.S. is clearly divided on whether or not Lyme is an easily cured disease with short-term antibiotics.

The Infectious Diseases Society of [North] America (IDSA) maintains that two to four weeks of oral antibiotics will cure Lyme disease. The International Lyme And Associated Diseases Society (ILADS) argues that Lyme spirochetes can evade and survive short-term antibiotic use. And ILADS stresses that many people who are infected with Lyme are also co-infected with other serious diseases. These co-infections make Lyme/+ much more complex to treat.

Juris Doctor Susan Ronn recalled, “The 2006 IDSA guidelines caused a stir in the media and action from Lyme advocate organizations. ILADS formally requested a retraction of the web-published guidelines previous to printing, based on the claim that the authors employed exclusionary data selection that substantially biased the resulting diagnosis and treatment recommendations while ignoring opposing or dissenting views about these recommendations.

“The journal refused,” Ronn noted.

Ronn pointed out, “IDSA has enjoyed the upper hand in the battle” in that the U.S. Centers for Disease Control, the National Institutes of Health and the Institute of Medicine has “accepted the society’s guidelines as the status quo.”

She added, “ILADS also publicly noted that adopted guidelines of the [North] American Academy of Neurology (AAN) mirror those of IDSA because the two committees contained overlapping authors.”

Ronn stated, “Both IDSA and ILADS wrote letter to members of the U.S. Congress regarding identical bills introduced in both houses, the Lyme and Tick-Borne Disease Prevention, Education, and Research Act of 2007, S. 1708 and HR 741. Neither bill progressed out of committee by the end of 2008, thereby killing the bills.”

Suzanne Shaps and J. David Kocurek, Ph.D., co-founders of the Texas group "Stand Up for Lyme," stress that the ruling guideline "is promoted by the [U.S. Centers for Disease Control] CDC and related agencies with the backing of the Infectious Disease Society of America (IDSA) through a peer cadre of academic physicians engaged primarily in research.

“The result is a history of literature which is self-serving and stagnant." ("Crisis of care: the Lyme controversy is costing Texans access to health care practitioners specializing in Lyme disease": www.standupforlyme.org)

Susan Ronn also emphasized the relationship of practice guidelines to clinical

experience: “Another issue invoked by the disagreement lies in the process used by medical societies to develop practice guidelines. IDSA has guidelines for its guidelines--rules to follow to ensure good science and fair and ethical practice. These rules state: Practice guidelines ... are never a substitute for clinical judgment. Clinical discretion is of the utmost importance in the application of a guideline to individual patients, because no guideline can ever be specific enough to be applied in all situations.

“Further,” Ronn pointed out, “one of IDSA's stated purposes for guidelines is clarification of controversy, and in choosing panel participants guideline developers are strongly encouraged to include members of relevant professional societies and to work toward consensus in their recommendations.”

“So who decides?” Ronn asked. “If the science truly remains uncertain, should patients have the right to knowledge about the disagreement? And, perhaps more importantly, should physicians be made aware of the disagreement, and the differing opinions regarding diagnosis and treatment modalities? (“In the Lymelight: Law and Clinical Practice Guidelines.” Southern Medical Journal, June 25, 2009; pp. 626-630; www.medscape.com)

Dr. Ann Corson, a physician in Cochransville, Pennsylvania--a state reeling from the Lyme/+ epidemic--observed, “Here we are in the worst state in the nation and doctors are misdiagnosing it all the time. They have patients coming in with typical symptoms of co-infections and they don't even know the co-infections exist. I came from the same Ivory Tower background as the IDSA doctors and the only reason I figured it out was because I opened my mind to a nonmedical person, and my son was dying.”

Dr. Corson concluded, “I consider myself a good diagnostician and it took me two years to figure out why my only child was dying. That doesn't mean there's something wrong with me; it means there's something wrong with my education.” (voicesweb.org, May 2, 2010)

Next: Patients and clinical doctors unite in historic coalition