
I was surprised. I had just settled into my long read of the 217 page new Institute of Medicine report on guideline reform (Clinical Practice Guidelines, We Can Trust, 2010), when the report took an amazing left turn. No, this is not the IOM report on Lyme disease (no telling when that comes out). This is the one on the need for medical guidelines reform in general—not just for Lyme disease. The IOM points to the Connecticut Attorney General investigation into the IDSA Lyme guidelines and says: “This case highlights the need for standardization and transparency in all aspects of systemic data collection and review, committee administration, and guideline development, so that questions about these issues do not detract from the science. [Guideline developers]... must be aware of the many, varied observers who will consider their development processes, particularly when their recommendations are likely to be controversial.” That’s a public slap on the wrist to the IDSA and it matters.

Oh sure, the IOM notes that some commentators called the AG action “politicization of professional practice guidelines.” But, the fact of the matter is that the IDSA Lyme guidelines are a poster child for why we need guideline reform. Why? Because, as the Connecticut Attorney General found, the IDSA 1) excluded divergent viewpoints, 2) handpicked their evidence, 3) didn’t screen for conflicts, and 4) held up
copycat guidelines (by the American Academy of Neurology) as independent when they were not. Don’t get me wrong. The IOM report presents both sides. The key thing is that slap on the wrist. *In public.* That means the IDSA is being held accountable and called out publicly for a shoddy guideline development process in its Lyme disease guidelines. As they should be! These guidelines make a mockery of the concept of evidence based medicine.

Those of you who follow this blog may know that Dr. Stricker and I have published peer reviewed articles about how the IDSA guidelines fail to follow the core principles of evidence based medicine. The IOM report cites one of our articles: Johnson L, Stricker RB. Attorney General forces Infectious Diseases Society of America to redo Lyme guidelines due to flawed development process. J Med Ethics. 2009; 35(5). Some of our other relevant articles include:


The IDSA is in the process of revising its new guidelines—let’s see if they can manage to get it straight this time. They are a huge organization, they have over 50 treatment guidelines, their annual revenues approach $10 Million dollars. The IDSA can afford to do it right and they owe it to the patients who have been harmed by their guidelines. The Lyme disease discussion in the report is in Chapter 3, pages 41 and 42.
What would they need to do, this time around? Take a look at the standards the IOM presents.

You can follow additional comments on Lyme policy at www.lymepolicywonk.org. You can contact Lorraine Johnson, JD, MBA at lbjohnson@lymedisease.org.