



FAO Dr Paul Mckeown, Health Protection & Surveillance Centre, Dublin Oct 21st 2015

I was interested to read today the full report of the Pennsylvania taskforce which had some interesting points about antibody blood testing & also made reference to the need for a more wider knowledge & acceptance of all guidelines with regards to Lyme disease - page 20 of the report is a good example of what they feel should be communicated to physicians in brochures so they are aware of the downside of antibody testing. Also that ILADS guidelines are updated & peer reviewed & on National Guideline Clearance Houses & should have as much respect as the IDSA guidance. I was wondering on the progress on the Irish taskforce & whether such advances are taking place? Have added below some useful links for you:

Pennsylvania Taskforce Committee Report Sep 2015:

Page 20 PREVENTION RECOMMENDATION 3: Standard Brochures for Physician

Distribution Develop and implement a standard brochure (based on the Virginia model) that physicians ideally should provide to patients when they are evaluated, either by clinical exam or lab testing, for potential Lyme and related tick-borne infections.

The brochure should clearly communicate that:

- “a negative result cannot rule out Lyme disease, based on current testing (2015) in early Lyme disease. You should talk to your doctor about your exam, results of other testing, and whether another diagnosis is likely based on your doctor’s judgment.”
- “certain tests for TBDs are based on the body’s immune response to the infection, which takes time to develop. If a specimen is collected too early, results may be falsely negative. Use of antibiotics before or at the time of specimen collection may also produce false negative results.”
- “science is emerging rapidly in tick-borne diseases.

Be aware that there are multiple schools of thought across the medical community regarding diagnosis and treatment of Tick-borne diseases. These are represented by multiple published guidelines available to HCPs through the National Guidelines Clearinghouse and medical professional organizations. These may include American Academy of Neurology (AAN), American College of Rheumatology (ACR), American Academy of Pediatrics (AAP) and American Academy of Family Physicians (AAFP) as well as IDSA and ILADS. Patients should discuss treatment with their healthcare provider’s approach.”

There is no gold-standard test for Lyme disease today, and patients should be properly informed of the significance of a negative test in absence of another likely explanation for their symptoms as determined by their doctor. It is well agreed upon

that testing is inaccurate in early Lyme disease (within 30 days of starting symptoms). The utility of testing in late Lyme disease is even more controversial. Furthermore, health care practitioners today have limited testing options for Lyme disease that are covered by insurance, that is, two-tiered antibody testing based on the CDC criteria for Western Blot interpretation and PCR testing of synovial fluid or cerebrospinal fluid appear to be the only two currently covered by some carriers.

END QUOTE

Source <http://www.health.pa.gov/My%20Health/Diseases%20and%20Conditions/L/Documents/Lyme%20Disease%20in%20Pennsylvania.pdf>

I have recently updated our western blot comparison sheet which explains why antibody testing can vary so much between labs & patient's diagnosis can be missed as a result:

<https://ticktalkireland.files.wordpress.com/2015/09/wb-comparison-by-jenny-update-2015.xls>

Plus studies on various methods of testing are available at:

<https://ticktalkireland.wordpress.com/lyme-links/testing/>

ILADS updated guidelines are available on the National Guidelines Clearinghouse:

<http://www.guideline.gov/search/search.aspx?term=lyme>

(number 2 in the list with IDSA, ILADS, EFNS & so on)

A recent article on 'Issues Surrounding Testing'

<https://ticktalkireland.files.wordpress.com/2015/04/issues-surrounding-testing.pdf>

I really hope that doctors be allowed to open their minds when it comes to diagnosis & treatment & NOT be restricted to IDSA only practises as per your [consensus statement](#) online. Is it possible to update this as suggested during a previous email to say that IDSA is a voluntary guideline & should not be used to replace the judgement of a practising physician as they state on their website?

http://www.idsociety.org/Guidelines_Patient_Care/

Plus add that ILADS guidelines (available on the National Guidelines Clearing House) are an alternative that could be considered after discussion with the patient, together with details on the pitfalls of testing?

I do hope the current Irish taskforce can take a lead from the Pennsylvania board so we can start to bridge the gap between ILADS & IDSA criteria, sadly patients are the ones falling between these gaps & it's our job to try & prevent this happening!

Thanks so much for your kind attention.

With best wishes,

Jenny O'Dea

Tick Talk Ireland

<http://www.ticktalkireland.org>

<http://ticktalkireland.wordpress.com/info/>

"Encouraging awareness, prevention & treatment of Lyme Disease (Borreliosis) in Ireland."