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Making Diagnostic Testing for Lyme Disease More Approachable

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Making Diagnostic Testing for Lyme Disease More Approachable

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Springfield, VT

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Lyme Disease: Confusing Tests; Confused Patients



- Even without diving into the scourge of “chronic Lyme,” understanding the diagnosis and treatment of Lyme disease can be difficult for patients and healthcare providers alike
- The two-step testing recommended by the CDC may not seem straightforward without some understanding of:
 - What is being analyzed in the blood sample
 - Why the sensitivity/specificity of these tests is important
- Many of the resources available to patients and healthcare providers are either too technical or too basic
- No single resource was identified that provided enough detail without becoming too confusing





The Cost of Tests and Medications

- One retrospective cohort study found that in California <20% of all tests for Lyme disease were ordered because the disease was actually suspected in the patient.¹
 - 35% were requested by the patient based on undue clinical suspicion
 - 41% were ordered as part of “screening tests” for nonspecific findings
- A study at Yale found that of ~200 patients referred for the presumptive diagnosis of Lyme disease >60% had no evidence of current or past infection yet had received an average of:³
 - 4 serologic tests
 - 7 office visits relating to Lyme disease
 - 42 days of antibiotics
 - 1 death related to inappropriate treatment⁴
- While no research has shown resource overutilization in Vermont, subjective evidence from clinicians is abundant





Community Perspectives



- JD (anonymized) presented to the clinic after being diagnosed with “chronic Lyme” at a holistic health center
 - She was placed on a “Lyme diet” of red meat and berries that was giving her diarrhea and making her feel “awful”
 - She claimed that her ELISA results were “equivocal,” was told that she “definitely had chronic Lyme disease”
 - She didn’t understand what the test results meant and didn’t understand what the test was even analyzing
- Victoria Sheehan, a staff nurse at the clinic, expressed some frustration with explaining intricacies/complexities of Lyme testing to patients during triage⁵
 - Details of IgM/IgG seroconversion and duration of immune response
 - When re-testing is indicated and if previous exposure = false positive
 - What duration of tick bite warrants testing

How Can We Help?



- Educating patients and clinicians about the recommended guidelines for testing, interpretation of test results, and the basic-science immunology behind Lyme disease may prove to be an inexpensive and easy intervention
- An educational document for use as an in-office guide and digital distribution was created using simple language to illustrate the sometimes complex concepts of:
 - The CDC's testing guidelines for when Lyme disease is suspected
 - The rationale behind two-tier testing relating to sensitivity/specificity
 - The roles/time-course of IgM and IgG in of Lyme disease
- The hope is that this document can be distributed or referred to as a starting point for any conversations concerning the sometimes confusing diagnosis of Lyme disease





Patient and Clinician Response

- Subjective responses from patients presented with information related to the previously mentioned education goals were positive:
 - “I never new any of this before. I wish someone had just taken the time to explain it to me.”
 - “I know that I shouldn’t trust all the crap on the internet... This makes a lot more sense.”
- Clinicians, unfortunately, didn’t have the opportunity to present any of the information to patients face-to-face or via phone triage, but thought that “it could be really helpful when I’m trying to jump between calls of a pregnant lady bleeding and someone who thinks that they maybe might have found a tick on their leg.”



Effectiveness and Limitations



- The educational document explains testing guidelines into easy to understand pieces with accompanying visual guides
 - One page (front and back) provides a single discrete page that can be distributed to patients and easily referred to
 - Digital format allows for distribution to patients during phone triage
 - Document addresses common concerns raised by clinicians and patients
- The document does not cover all concerns that might be raised by patients
 - Much of the complexity and subtlety of testing can not/was not conveyed given the length/wording of the document
 - “Chronic Lyme Disease” was found to be a very common concern amongst patients and was intentionally NOT addressed in this document

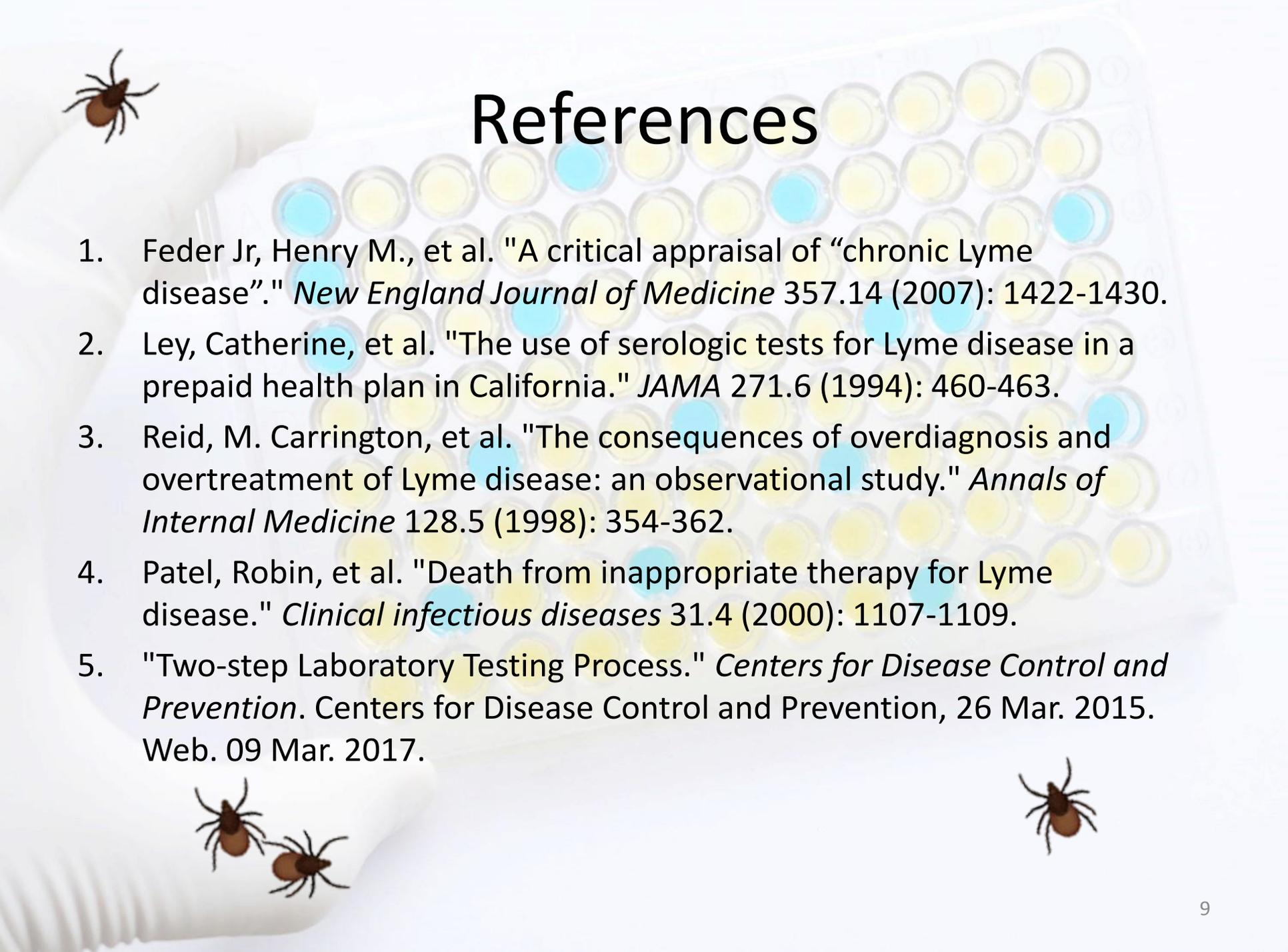




Future Ideas

- Keep the document in digital form to allow for easy updating if there are any changes in testing guidelines
- While this document does a good job of covering information in an appropriate level of depth it is not especially pretty and could use additional work to allow for greater legibility
- Create a separate document to cover “Chronic Lyme Disease”
 - Major area of concern to many patients
 - Sometimes very difficult to talk about with patients
 - Information to act as a starting point for conversations with patients
- Receive more feedback that might be used to further update the document to ensure that it covers key areas of concern to patients that it might currently be missing



A hand holding a white medical device, possibly a pipette or a small container, with a spider on it. The device has a grid of yellow and blue circles. The background is white with a subtle pattern of yellow and blue circles.

References

1. Feder Jr, Henry M., et al. "A critical appraisal of "chronic Lyme disease"." *New England Journal of Medicine* 357.14 (2007): 1422-1430.
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4. Patel, Robin, et al. "Death from inappropriate therapy for Lyme disease." *Clinical infectious diseases* 31.4 (2000): 1107-1109.
5. "Two-step Laboratory Testing Process." *Centers for Disease Control and Prevention*. Centers for Disease Control and Prevention, 26 Mar. 2015. Web. 09 Mar. 2017.

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Lyme Disease
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3/1/2017

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The interviewer affirms that he/she has explained the nature and purpose of this project.

The interviewee affirms that he/she has consented to this interview.

Yes

Name: Victoria V Sheehan

Name: _____

If not consenting as above: please add the interviewee names here for the Department of Family Medicine information only.

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