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Beyond Acute Lyme

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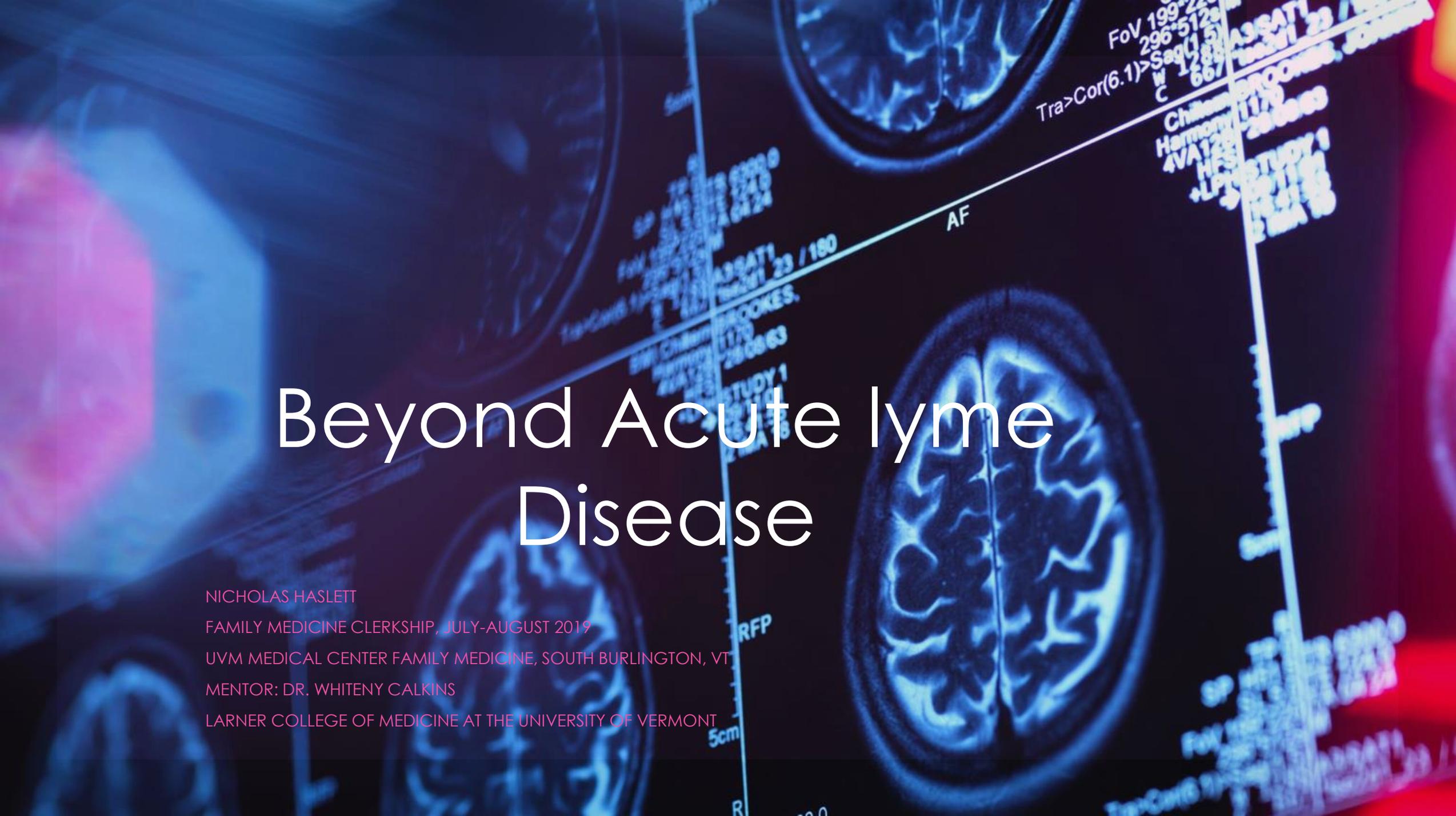


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Beyond Acute Lyme Disease

NICHOLAS HASLETT

FAMILY MEDICINE CLERKSHIP, JULY-AUGUST 2019

UVM MEDICAL CENTER FAMILY MEDICINE, SOUTH BURLINGTON, VT

MENTOR: DR. WHITENY CALKINS

LARNER COLLEGE OF MEDICINE AT THE UNIVERSITY OF VERMONT

Problem Identification

- ▶ Lyme Disease is a preventable potentially multisystem bacterial infection spread by the bite of *Ixodes Scapularis* (aka deer tick, black-legged tick, bear tick)
- ▶ Vermont has become the second-most Lyme-infected state in the country, according to the CDC
- ▶ The CDC identifies the persistence of Lyme symptoms after successful antibiotic treatment of Lyme disease as Post Treatment Lyme Syndrome (PTLS)
- ▶ A growing number of people believe that they have Chronic Lyme, and there is controversy over what this term means, and whether it is legitimate
- ▶ Greater medical literacy is needed and broader cultural competency required to effectively understand and counsel patients who believe they have, or have even been diagnosed with, “Chronic Lyme”

Lyme Rates in the Five Highest-Incidence U.S. States

Rate of new cases annually per 100,000 people

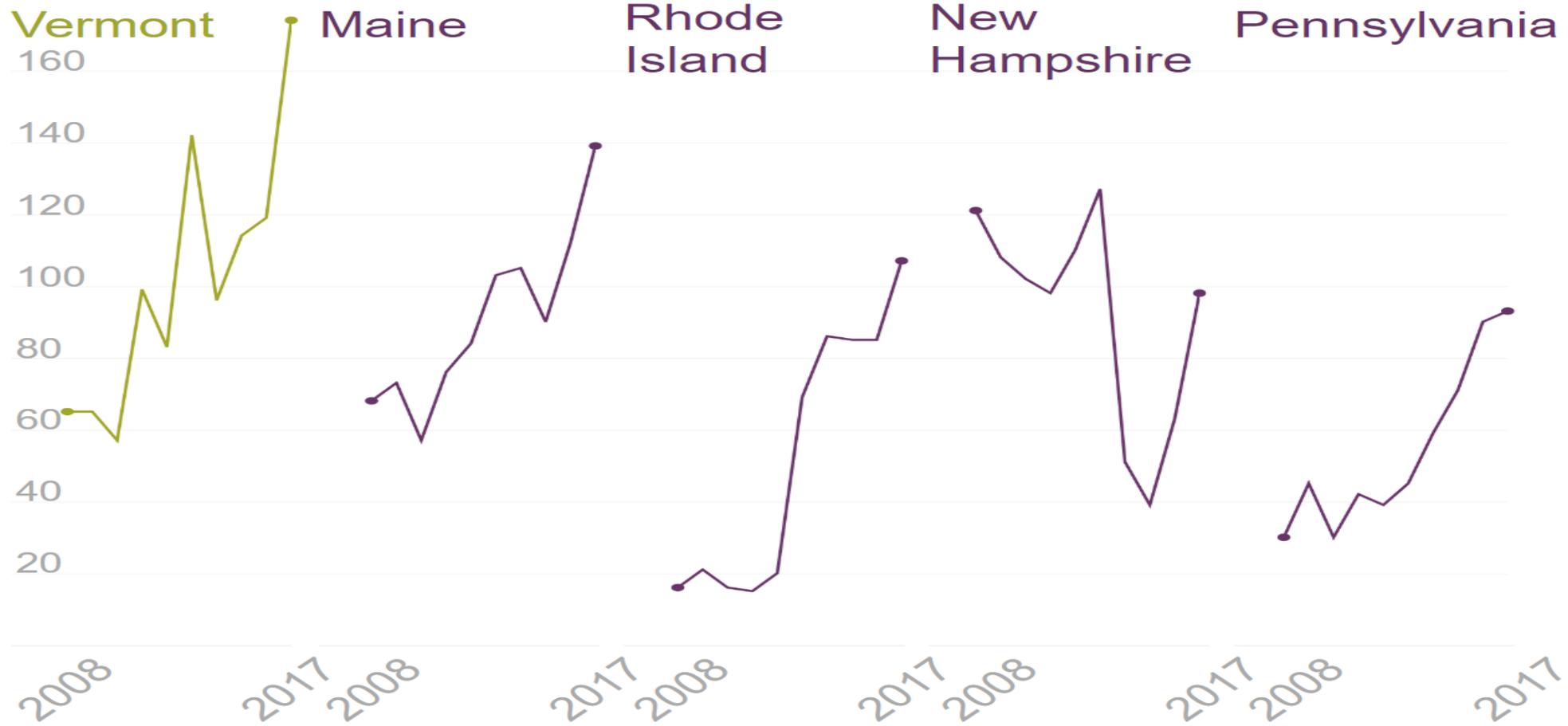


Chart: Andrea Suozzo • Source: Centers for Disease Control, U.S. Census Bureau

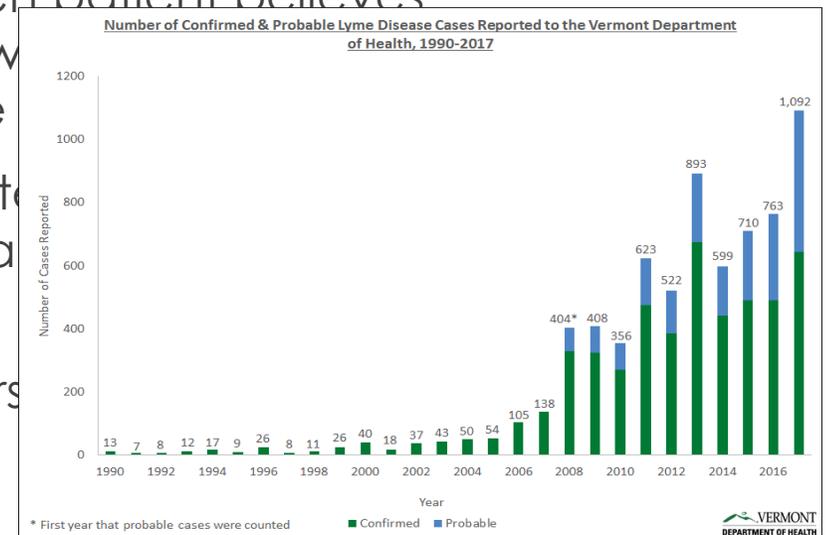
Public Health Cost

- ▶ **“Total direct medical costs attributable to Lyme disease and PTLDS could be somewhere between \$712 million - \$1.3 billion each year”** Adrion ER, Aucott J, Lemke KW, Weiner JP (2015) Health Care Costs, Utilization and Patterns of Care following Lyme Disease. PLoS ONE 10(2): e0116767.

- ▶ Unquantifiable cost to patient-physician relationship when patient believes they have, or has been diagnosed by another provider with Lyme” and physician is dismissive of patient's experience

- ▶ Patients seek other diagnostic testing and treatments, often incurring financial and physical cost to the individual and potential harm to the community and field of medicine

(e.g. antibiotic resistance brought about by prolonged courses of treatment)



Community Perspective on Issue

- ▶ “I think that people have symptoms in the setting of a history of Lyme disease. It's hard to make a connection that the symptoms are due to Lyme disease. It may be that there is a chronic Lyme symptom syndrome, but I don't believe that treating it with further antibiotics is going to be helpful. So I feel very stuck when people have those symptoms because I would like to be able to help them, but I don't know if there is a treatment that helps them other than symptomatic treatment.” Dr. Clara Keegan, Family Medicine Physician at UVM Medical Center
- ▶ “I do my best to recognize that the wide array of symptoms that people may attribute to chronic Lyme is often coming from an explicitly different system of thought. It's not my training, it's not where I'm coming from. There are different ways to recognize Lyme disease, and some of them are hard for me to accept based on what I know and my training. I know other clinicians whom I can respect are doing it that way. I am often just not on board with the antibiotics aspect of it. There's a different kind of cultural competency needed there I guess.” Dr. Peter Bingham, Pediatric Neurologist at UVM Medical Center

Intervention and Methodology

- ▶ Created information sheet for providers and patients, with references cited, accessible both within EMR and as a printout, that provides informed perspective on efficacy of different diagnostic procedures, data on long-term antibiotic usage in context of Lyme disease
- ▶ Distinguish between Post Treatment Lyme Syndrome and chronic Lyme disease
- ▶ Discuss implications of lack of supporting data for alternative treatment modalities
- ▶ Ask Family Physicians to share pamphlet information with relevant patients and seek patient perspective

Results/Response

Positive feedback from physicians about having an easily accessible sheet for providing helpful information to patients asking about validity of alternative testing and treatment methods

Enthusiasm from physicians and patients about creating space for less caustic dialogue about contentious issue that has, in the past, involved patients accusing physicians of negligence and physicians describing mass hysteria around specter of chronic Lyme.

Skepticism from patients that most physicians are willing to put in the time “to understand chronic Lyme.”

Evaluation of effectiveness and limitations

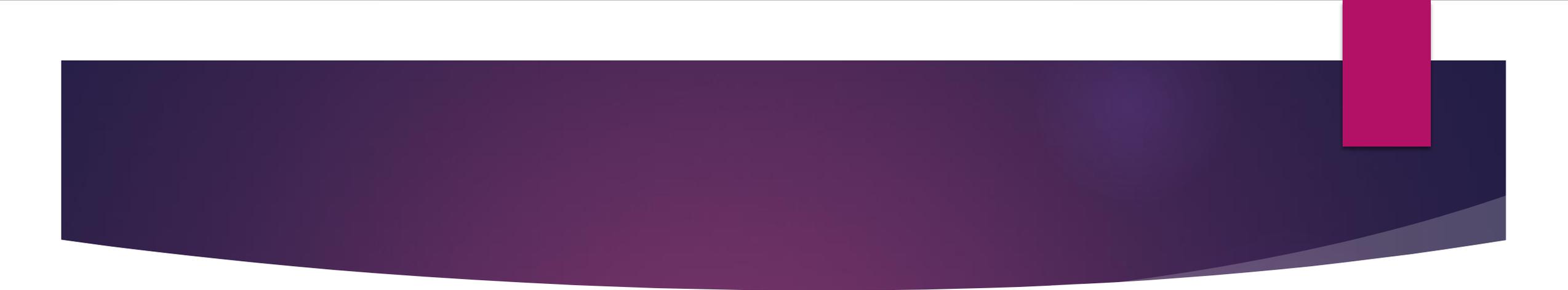
- ▶ Generate Pre-appointment survey to patients on knowledge of Lyme testing, prevention and treatment options
- ▶ Generate Post-appointment survey after receiving the information from a chronic Lyme/post-treatment Lyme handout
- ▶ Limitations: potential cultural barriers, straight-up people who don't necessarily have access to health care (maybe missing people who don't use doctor's office services and so are more vulnerable)

Future Interventions

- ▶ Develop tool for keeping up-to-date information available as testing modalities change
- ▶ Tick-borne illness information sessions and support groups
- ▶ Provide data sheets with rates and types of side effects from prolonged IV antibiotic usage,
- ▶ Provide information to make sure patients understand implications of antibiotic resistance

References

- Brian A. Fallon, Martina Pavlicova, Samantha W. Coffino, Carl Brenner, A Comparison of Lyme Disease Serologic Test Results From 4 Laboratories in Patients With Persistent Symptoms After Antibiotic Treatment, *Clinical Infectious Diseases*, Volume 59, Issue 12, 15 December 2014, Pages 1705–1710, <https://doi.org/10.1093/cid/ciu703>
 - Adrion ER, Aucott J, Lemke KW, Weiner JP (2015) Health Care Costs, Utilization and Patterns of Care following Lyme Disease. *PLoS ONE* 10(2): e0116767.
 - Lantos PM, Shapiro ED, Auwaerter PG, et al. Unorthodox alternative therapies marketed to treat Lyme disease. *Clin Infect Dis*. 2015;60(12):1776–1782. doi:10.1093/cid/civ186
- <https://www.niaid.nih.gov/diseases-conditions/chronic-lyme-disease>
- <https://www.healthvermont.gov/disease-control/tickborne-diseases/lyme-disease>
- <https://www.cdc.gov/mmwr/preview/mmwrhtml/00038469.htm>

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- ▶ Thank you for agreeing to be interviewed. This project is a requirement for the Family Medicine clerkship. It will be stored on the Dana Library ScholarWorks website. Your name will be attached to your interview and you may be cited directly or indirectly in subsequent unpublished or published work. 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.
 - ▶ Consented
 - ▶ Name: Clara Keegan, MD, University of Vermont Medical Center
 - ▶ Name: Peter Bingham, MD, University of Vermont Medical Center
 - ▶ Did not consent:
 - ▶ Name: anonymous patient