

Chairman Fisher and members of the House Health Care Committee,

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and LYME

My name is Ellen Read. I am an RN from Saint Albans. I have been infected and treated successfully twice with long term oral antibiotics. This has meant the difference between incapacitation and return to a useful, productive life. I have had to go outside of Vermont to find this treatment. I have been an advocate for Vermonters affected by TBD's since 2005.

On behalf of Vermonters dealing with the chronic effects of tickborne diseases (TBD's), thank you for inviting us back as a follow up to the hearing you held last March. We hope to update your group on the status of those of us seeking care, and look forward to Commissioner Chen's report.

With your permission, I would like to tell you what we hope to hear from Commissioner Chen. Then I wish to relate to you difficulties Vermonters currently face when seeking adequate treatment for chronic, often debilitating infection.

Dr. Chen had been invited to each of the support group meetings held in South Burlington since last March. Neither he nor a representative has attended. We were not asked for any suggestions or input from the VDH.

We are hoping that his recommendations to your committee will include the following:

- ① -more psas before and during high season for tick bites (April through November, roughly), especially during the Green-up activities each spring, in advance of sugaring, and before and during hunting season.
- ② -making available to school nurses through the statewide AHEC program a ready to use set of curricula which has been on file with the state education department since March of 2008. It has modules for Kindergarten, primary, middle and high school ages. There has been a 5 year delay in utilizing a tool that is so well planned that a substitute teacher could present it. VDH is aware of the curriculum.
- ③ -collection of ticks at deer reporting stations during hunting season. Collecting specimens in this way would be a way to map known TBD infection rates in ticks with a minimum of effort and cost. Locations of kills would be available from hunters to "put pins in the map." Fish and Game wardens would need minimal training for this. It would represent a more scientific approach than the opportunity for people to log in to the VDH reports of ticks that they had found in Vermont. I myself tried to access that three times this summer, without success. This project also assumed that those reporting could verify that a tick was in fact a black legged (or "deer" tick).
- ④ - an effort that goes beyond recognizing the winner of a high school video contest for a psa on Lyme disease.

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- inclusion in the training of licensed vocations in Vermont for recognition and reporting of suspicious rashes and deer ticks, and proper removal of embedded ticks. This would include but not be limited to health care providers and technicians, hairdressers, massage therapists or in short, anyone who might observe and report the earliest signs of infection.

I would like to report to you that, as an RN, I attended the VDH educational program on vector-borne diseases, i.e. WNV, EEE and Lyme on April 6, 2013 at the WRJ VA Hospital sponsored by that area's AHEC. This was soon after our presentations to your committees. The two schools of thought regarding the existence and treatment of chronic Lyme disease were presented by Dr. Christopher Grace from FAHC, whom you had heard as a presenter in this room on April 10, last year as a counterpoint to our presentation, and Jeff Wulfmann, MD, who has but no longer treats patients with chronic Lyme disease. He has a teaching position at UVM School of Medicine. Dr. Wulfmann presented after Dr. Grace.

In a most curious manner, Dr. Grace was then asked by Dr. Chen as moderator, "if he would critique Dr. Wulfmann's presentation." This was an awkward and embarrassing moment for those in attendance, as well as for Dr. Wulfmann.

It is of great concern that the VDH has been used as a bully pulpit by FAHC's Infectious Disease department to promote ONLY the protocol of the IDSA (Infectious Disease Society of America). Those doctors wishing to follow an alternate protocol which recognizes chronic infection from TBD's do indeed feel pressure to conform to the "party line." We who are infected are caught between the proverbial rock and a hard place. It is the role of health departments to track disease and inform the public of disease presence and prevention. If the VDH continues to participate in what by rights should be a discussion in the medical community, we will see no open discussion for alternate choices for our care. Insurance companies will justify withholding "unacceptable" treatment with no hope of appeal.

When the terrible disease AIDS came on the scene, in order to find as quickly as possible what worked, treatment options were greatly expanded – including many off-label uses of available drugs, combinations of drugs and experimental treatments. Our options continue to be stymied by medical politics. This is why we return yearly, seeking a political solution from your committee. For now the sixth year, our group is trying to explain to our legislators the untenable situation in which we find ourselves. The guidelines of IDSA holds sway because they were the first published. They remain virtually unchanged since the 1990's, as have the laboratory tests which are recognized by CDC as inadequate for certain diagnosis. The references to four studies relating to long-term use of antibiotics date from 2007, 2006, 2001, and 2003. Their reports of complications from indwelling IV's are quoted in the VDH newsletter are from 1990-1992. For proper context, rates of infection for ALL long term catheter use should be presented. Since most long term abx given for Lyme disease are given by the preferred oral route, the published newsletter sent to medical providers borders on sensationalism and fear mongering .

The guidelines of the International Lyme and Associated Diseases Society which originated from but have been expanded beyond those of the IDSA are also filed with the National Clearinghouse, but not

referred to by FAHC, the VDH, or IDSA. Many of its members are Infectious Disease specialists who do not agree with their Association's Guidelines. Currently there is pressure on the CDC from grass roots organizations and members of Congress to review and expand guidelines for TBD's.

For those like myself for whom the currently sanctioned treatment failed, finding a doctor who uses a treatment option of carefully monitored and rotated abx can provide a return to health.

By and large the biggest problem voiced by attendees to the support groups is the frustration of being told by providers that there is only one treatment option available to them. If this treatment fails them, they are told that Lyme is not a chronic infection, and that it is no longer the problem. Thus, they are declared cured of Lyme by definition, but remain sick with no treatment options unless they are willing to go out of state and find an ILADS doctor. Many complain of extensive and expensive but inconclusive testing.

The model for health care is: awareness, education, screening, early intervention and appropriate and complete treatment. This is not currently in place for addressing TBD's.

> 2 AWARDS IF TIME PERMITS.

We are hoping to hear from the Commissioner today, a presentation on Lyme and TBD's as a public health issue. We hope to hear from him about the effects it is having on Vermonters, not a further defense of IDSA protocol. We want to know when it will be considered an epidemic. We have to know 887 new recognized cases in 2013 are being taken seriously by him, and that he understands the cost of these numbers. ^{TAKING 2011, 12, 13 = 2,000 CONFIRMED + PROBABLY CASES REPORTED BY VDH -} If 10 - 40% ~~of~~ Vermonters remain ill after the only available guidelines fail them. ^{THAT'S 200 TO 800}

If and we do nothing to change their options, then we have all failed them. ^{THE COSTS INCURRED FOR LOST WORK, PLUS CLAIMS FOR DISABILITY OR WORKMANS COMP ARE MOUNTING.}

We know that desperately ill people may seek desperate measures to regain their health and livelihoods. We also know there are unscrupulous profiteers waiting to prey on those who feel they have no good solutions. Please consider the risks in not expanding legitimate medical choices if this bill is left to languish. In NH the year after passing similar legislation saw an increase in doctors willing to specialize in treating chronic TBD's. This result is our goal for Vermonters.

We ask you, the legislators, for your support of H.123, not as a mandate for treatment but to allow options not currently ^{COSTLY} available. Again, it is a simple, laissez-faire and cost free approach to begin to address a very real and growing health threat to Vermonters.

Thank you for your time and consideration.

