

TESTIMONY BEFORE THE  
HOUSE HEALTH COMMITTEE

Public Hearing on Lyme Disease and Tick- Borne Illness Information

Monday, September 9, 2019

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PA LYME RESOURCE NETWORK

Thank you, Representative Brown, Representative Rapp and House Health Committee members for the opportunity to speak on this critical PA health issue. My name is Michele Cassetori. I am an Occupational Therapist with 29 years of experience, and I work as Director of Occupational Therapy for a provider serving four counties. I am also an adjunct faculty member at Misericordia University and a PA Lyme Resource Network Board Member.

Pennsylvania is #1 in reported cases of Lyme Disease (LD) for 7 years running. In 2017, there were 119,000 new cases. It is also very important to note that 30% of LD cases in PA are children who continue to be the most impacted group.

As an Occupational Therapist, I have seen the effects of illness on patients, but it was seeing the suffering of my own children that had the greatest impact on me as a mother and a health care provider. In the past few years, within my practice I have seen an increase in the number of patients referred for therapy due to effects of LD. Many of them had been diagnosed late or denied ongoing medication treatment which led to significant health issues. A woman in her late 40's now wheelchair bound, desperately trying to keep her clerical job, but struggling due to extreme fatigue, weakness, coordination and cognitive difficulties; a first responder out of work due to physical dysfunctions related to late diagnosed LD. And there are my 2 daughters – my oldest at the age of 20 – a highly conditioned, competitive college distance runner suffering with scary cardiac symptoms, suddenly sidelined from her role as a student athlete. Shortness of breath and chest pain just from walking across campus to class. Or my younger daughter who,

now a HS senior, has yet to complete a full, traditional year of HS due to debilitating fatigue and neurological symptoms. I have seen first-hand at home and in the clinic the effects of LD:

- Physically – loss of mobility, strength, coordination, and sensory deficits
- Cognitively – difficulty with concentration, memory, problem solving, even direction following and speech
- Psychologically – depression, anxiety, panic attacks, OCD, and anger issues
- Social participation – difficulty engaging in conversation and interactions which led to social isolation

As a professional, I also know from experience that the most successful treatment plans are those designed with collaboration from the patient and the physician and that are covered by insurance. It is critical to outcomes and drives evidenced based treatment approaches. The treatment approach for patients with LD should be no different. Allison DeLong, Biostatistician from Brown University concluded that a careful statistical analysis of the 4 NIH (Lyme) treatment trials revealed that: “for some patients with Lyme Disease, retreatment can, in fact, be beneficial.” Dr. Yang Zhang, a Professor from John’s Hopkins University, researching Lyme Disease concluded “The more prolonged the infection or delayed diagnosis the more likely persistent infection that is more difficult to treat would develop. This is also true for other persistent infections like Tuberculosis. It is well known that if you allow infection to go on longer before treatment it becomes harder to treat...We found that the current antibiotics for treating Lyme Disease are unable to kill the persister forms of Borrelia. We need...drugs in combination for 6 months to cure Tuberculosis. In the case of Lyme, the current guideline is too simple. The current Lyme treatment is only good for the active form...but not so good for treating the persistent form of the disease.” <https://on-lyme.org/en/sufferers/lyme-stories/item/257-new-research-sheds-light-on-chronic-lyme>

In the spirit of Act 83, patients and health care providers should be educated and have access to the broad spectrum of treatment options for all stages of LD. This approach, with insurance coverage, would allow for patient choice in their treatment and provide an opportunity for the best patient outcomes. Individualized treatment, when deemed medically necessary, should be covered by insurance. Patient’s with LD should not be denied access to treatment

which can potentially improve their quality of life and prevent chronic, debilitating illness and dysfunction. We know that when it comes to LD, current diagnostics are inadequate and patients are therefore very often diagnosed late, so doesn't it make sense that their course of treatment may need to be different, perhaps longer than an acute case of LD? When caught and treated later, 40% of patients do not recover with short-term treatment. Without adequate treatment, chronic illness is almost certain to occur with devastating impacts:

- For children and young adults – our most impacted group – a loss of educational opportunity, loss of play/leisure roles and even a loss of basic self-care skills
- For adults – loss of work / financial devastation and loss of role identity

In my experience, I can tell you that proper treatment can make a difference:

- The woman in her late 40's began walking short distances and was able to keep her job as a productive employee.
- My now 21-year-old daughter is back to running, up to 12 miles a day, captain of her XC team and started her senior year in college.

These cases were diagnosed later, and short-term treatment failed, so they sought treatment beyond the original round of antibiotics recommended by the CDC. These cases incurred out-of-pocket expenses due to a lack of insurance coverage for the treatment duration it took to get them well.

In summary, looking ahead WE NEED:

- healthcare practitioners to be educated on the broad spectrum of treatment / medication options;
- continued public awareness and prevention education;
- research in the area of diagnostics and treatment;
- insurance coverage for patient access to physician visits, diagnostics and long-term treatment options, particularly for those with symptom progression; and
- HB 629 legislation to ensure that a lack of insurance coverage will NOT be a barrier to patient access to proper, effective treatment to restore their quality of life and prevent suffering and dysfunction associated with chronic illness.

# LYME DISEASE

DEBUNKING MYTHS WITH FACTS



## DOCTORS ARE TREATING LONGER.

WHEN SHORT-TERM TREATMENT FAILS, PATIENTS NEED OPTIONS!

A CDC study shows that in actuality, 56% of patients were treated LONGER by their physicians and NOT using the short-term approach often recommended.

Protect the Physician - Patient Relationship!

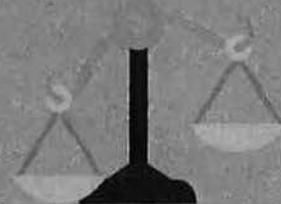


## LONG-TERM ANTIBIOTICS ARE 99% SAFE.

A SAFE OPTION FOR PATIENTS IN CRITICAL NEED!

As demonstrated in multiple LARGE studies, long-term antibiotic treatment presented a LESS THAN 1% rate of adverse events. This is among the safest of all medicines.

The patient should decide risk/benefit.



## LETTING LYME PROGRESS IS DANGEROUS.

WHERE THE REAL RISK LIES.

The World Health Organization recognized that progressive Lyme and tick-borne disease can lead to serious and life-threatening conditions: dementia, central nervous system demyelination (MS-like), cardiac disease (carditis) and polyneuropathy (nerve damage).

\*In 2018 the WHO revised ICD11 codes to reflect impact of progressive Lyme disease.



# LYME DISEASE

PASS HB629 TO PROVIDE FAIR ACCESS TO TREATMENT



30% Children

**IT'S AN EPIDEMIC.**

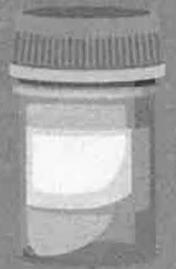
**LYME DISEASE IS A BIG PROBLEM IN PA!**

Pennsylvania is #1 in reported cases of Lyme Disease for 7 years running. In 2017, there were 119,000 cases. 30% of reported cases are children and youth.

**40-50% FAIL SHORT-TERM TREATMENT.**

**EARLY DISEASE IS NOT THE SAME AS LATE DISEASE!**

When caught and treated early, 10-20% of patients do not recover with short-term treatment. When caught and treated later, 30-50% of patients do not recover with short-term treatment.



**LONG-TERM TREATMENT IS RATIONAL.**

**EQUAL EVIDENCE SUPPORTS LONG-TERM TREATMENT!**

**Brown University's Allison DeLong, Biostatistician, MS.**



A careful statistical analysis of the 4 NIH [Lyme] treatment trials revealed that: "for some patients with Lyme disease, retreatment can, in fact, be beneficial. Krupp's study detected significant, sustained, clinically meaningful improvement in fatigue. Fallon's study corroborated this and found that pain and physical functioning also had significant and sustained improvements. It is therefore wise for clinicians to disregard generalized and unsupported recommendations against retreatment, and instead rely on their clinical judgement to manage patients with persistent symptoms of Lyme disease."



**John Hopkins University's Yang Zhang, MD, PhD**

The more prolonged the infection or delayed diagnosis the more likely a persistent infection that is more difficult to treat would develop. This is also true for other persistent infections like Tuberculosis... it is well known that if you allow the infection to go on longer before treatment it becomes harder to treat or eradicate... We found that the current antibiotics for treating Lyme disease are unable to kill the more resistant persister forms of Borrelia. We need... drugs in combination for 6 months to ...cure Tuberculosis. In the case of Lyme the current guideline is too simple. The current Lyme treatment is only good for the active form.. but not so good for treating the persistent form of the disease.