

Pennsylvania HB629 Rally – Harrisburg, PA, October 22, 2019

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I am a psychiatrist in New Jersey who has treated thousands of Lyme patients in the past 30 years and many have come from Pennsylvania. I am here to support passage of Pennsylvania HB629.

Our greatest resource is our human capability and productivity and that is being jeopardized by an epidemic of inadequately diagnosed and inadequately treated tickborne diseases in children and adults. A significant amount of mental illness and other types of mental dysfunction are attributable to brain injury caused by persistent immune dysfunction associated with a long list of chronic infections, and in particular tick-borne infections. Since there are current barriers to diagnosis and treatment, I see the human cost of inadequate treatment. This includes suicide, homicide, mental illnesses, disability, developmental disabilities, pain, suffering, caretaker burden, lost productivity, and economic losses. The main cause of death from Lyme disease is suicide. I have treated many suicidal Lyme patients from Pennsylvania. Based upon epidemiological studies there are about four hundred suicides per year in Pennsylvania caused by Lyme disease. I have also evaluated cases involving 6 homicides in Pennsylvania attributable to Lyme disease and I am sure there are many more where the association is not recognized. A number of Lyme disease patients die from opioid and other substance abuse. I have done research demonstrating inadequately treated Lyme disease results in disease progression with an expansion and an intensification of a broad spectrum of multisystem symptoms that can be different in each patient. These impairments include general medical and neuropsychiatric symptoms. Inadequately treated Lyme disease can result in autism spectrum disorders, schizoaffective disorders, bipolar disorder, depression, anxiety disorders, eating disorders, sleep disorders, addiction, opioid addiction, cognitive impairments, dementia, seizures, dissociative episodes, and other impairments. But the good news is we can prevent some of this epidemic of suicide, mental illness, substance abuse, and violence with effective diagnosis and treatment. Isn't that the purpose of a healthcare system and insurance?

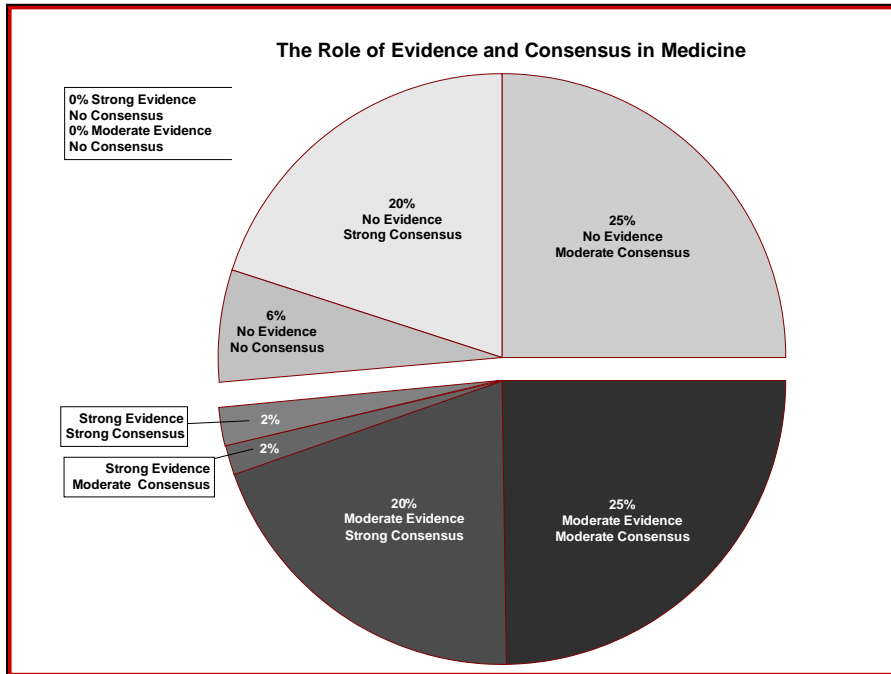
The opposition to this bill argues that improving access to long-term antibiotics is dangerous, unnecessary, and expensive. The opposite is true. Individualized treatment, not third-party one size fits all tyranny, is the standard of care and only individualized treatment improves safety, medical necessity and cost.

Individualized treatment is the standard of care

It is important to first point out that all treatment must be individualized based upon evidence-based medicine, which is the combination of the best evidence available, physician judgment and patient preferences. All medical knowledge is on a continuum of different degrees of certainty. There is conflicting evidence, conflicting consensus and conflicting guidelines involving Lyme disease. Scientific evidence and consensus are shifting towards recognizing that Lyme disease is a chronic infection that can benefit from extended antibiotic treatment in some patients. Based upon individualized assessment, if there is an indication a patient does or may

benefit from antibiotic treatment; it would be unethical and a deviation below the standard of care not to offer it to them.

Who should make this treatment decision, the treating physician or an insurance company executive?



Institute of Medicine

A 2013 CDC study found that the majority of Lyme disease patients (56%) are being treated with antibiotics for longer than the length recommended in the highly controversial IDSA guidelines. In addition, the American Psychiatric Association ([Psychiatric Evaluation of Adults Practice Guidelines, Third Edition \(Aug 2015\)](#)) recognizes the significance of Lyme disease causing psychiatric symptoms and the International Classification of Diseases (ICD-11) has 15 codes for Lyme disease that recognize the serious chronic manifestations.

ICD-11 Lyme Codes

- 1C1G Lyme borreliosis
- 1C1G.0 Early cutaneous Lyme borreliosis
- 1C1G.1 Disseminated Lyme borreliosis
- 1C1G.10 Lyme Neuroborreliosis
- 1C1G.11 Lyme Carditis
- 1C1G.12 Ophthalmic Lyme borreliosis
- 1C1G.13 Lyme arthritis
- 1C1G.14 Late cutaneous Lyme borreliosis
- 1C1G.1Y Other specified disseminated Lyme borreliosis
- 1C1G.1Z Disseminated Lyme borreliosis, unspecified
- 1C1GY Other specified Lyme borreliosis

- 6D85.Y Dementia due to other specified diseases classified elsewhere: Dementia due to Lyme Disease
- 9C20.1 Infectious panuveitis: Infectious panuveitis in Lyme disease
- 9B66.1 Infectious intermediate Choroiditis: Infectious intermediate uveitis in Lyme disease
- 8A45.0Y Other Specified white matter disorders due to infections: Central Nervous System demyelination due to Lyme borreliosis

So why does current Pennsylvania insurance policy deviate below these standards?

Safety

All of medicine involves a highly individualized risk vs. benefit decision making. What is the risk of the disease vs. the risk of the treatment in that patient? There are risks associated with antibiotic treatment. Antibiotics can potentially have side effects. Acne is less serious than Lyme disease and many are treated for years with antibiotics without serious adverse effects. An extensive study by the CDC was able to identify only one death caused by Lyme disease antibiotic treatment.

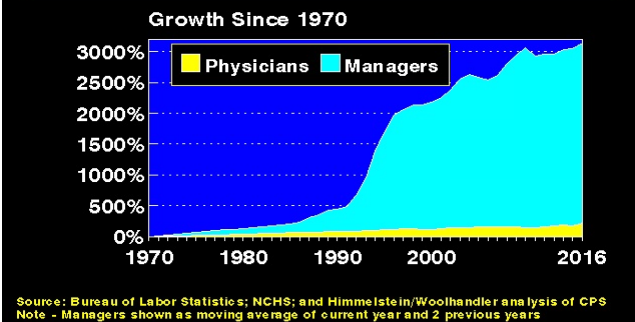
In contrast to the relatively low risks associated with antibiotic treatment what are the safety risks of inadequately treating Lyme disease? I see the patient who went undiagnosed and undertreated with serious consequences. The risk of not treating includes deaths impairments, disability, pain, suffering, caretaker burden and lost productivity.

Cost

The antibiotics used in the treatment of Lyme and other tick-borne diseases, such as doxycycline and ceftriaxone are mostly reasonably priced generics. Anyone can look this up on GoodRx.com. a month of doxycycline is \$19.55 and a 2-gram vial of ceftriaxone is \$6, without insurance when we avoid the predatory middlemen.

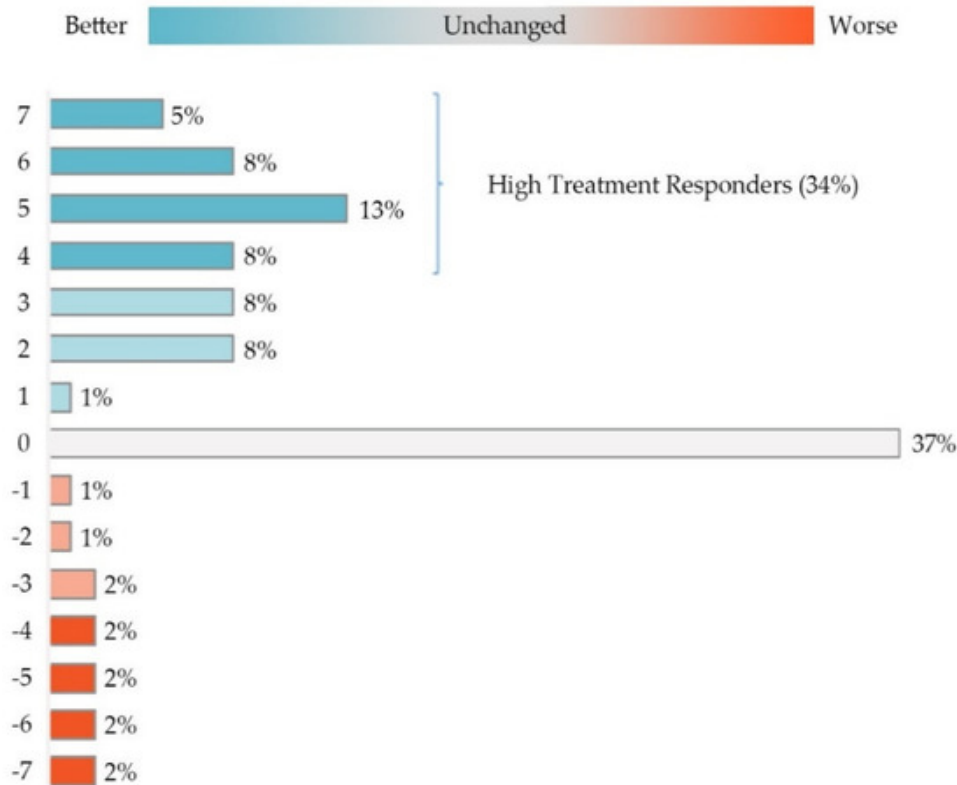
We all know the cost of healthcare is exploding. Doctors aren't earning more; patients aren't getting more, and the cost of drugs has remained at 10% of healthcare costs for 50 years. Where is all that money going? There is an ever-increasing expense associated with healthcare middlemen. Healthcare administrators have increased by over 3000% in the past 50 years and healthcare is being managed to death. Insurance company executives are being paid multi-million-dollar salaries. Is some of that middleman money going to politicians to obstruct legislation such as this? People buy insurance with the expectation it will cover them when they become ill. Why should seriously ill patients be forced to deal with dishonest insurance companies that take their premiums, keep the money and deny their claims?

Growth of Physicians and Administrators 1970-2016

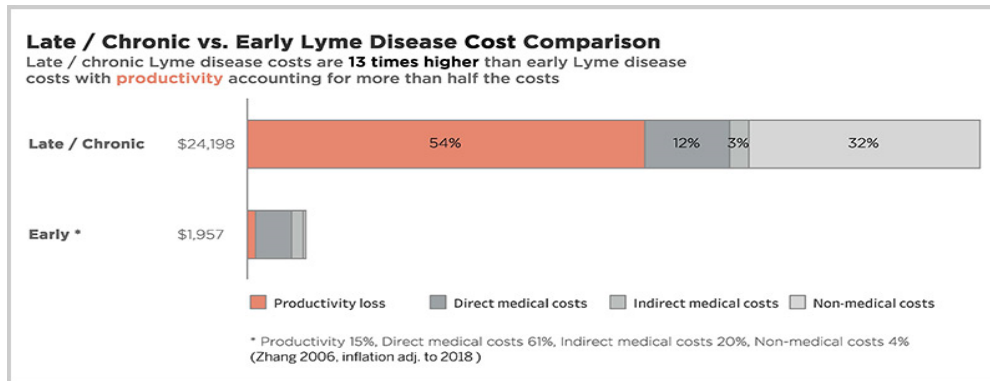


When the restrictive 2006 IDSA guidelines were published, I challenged the validity of these guidelines and this was supported by the Medical Society of New Jersey and the New Jersey Psychiatric Association. I wrote a similar peer reviewed journal article rebuttal to their proposed 2020 guidelines. When insurance companies follow scientifically unsound restrictive guidelines it increases the societal burden of chronic disease, it drives mainstream away from the treatment of Lyme disease and encourages other to fill the void with less appropriate and less effective treatments.

Degree of change reported by Lyme disease patients after treatment.



LymeDisease.org 2015 survey of 6100 Lyme patients



In summary

Individualized treatment, including longer courses of antibiotic treatments for Lyme disease, are the standard of care and promote patient safety, reduce total societal costs and are medically necessary. Pennsylvania Senators have an opportunity to promote health and productivity when they vote yes for HB629.

We all value human dignity, and honesty. We also have a passion for freedom and a resistance to any form of tyranny. Our ancestors were at Valley Forge, Gettysburg and Normandy and our family members are currently throughout the world to preserve freedom. My son has been deployed four times, and just returned from the Middle East. But we also need freedom at home, and the freedom to access the medically necessary healthcare treatments for Lyme disease. Freedom in healthcare is as critical as the freedom of speech or religion or any other basic freedom. As Dr. Benjamin Rush, signer of the Declaration of Independence and personal physician to George Washington stated— “Unless we put medical freedom into the Constitution, the time will come when medicine will organize into an undercover dictatorship to restrict the art of healing to one class of men and deny equal privileges to others. Physicians in Pennsylvania today should have the same freedom to treat their patients that my ancestor, Dr Thomas Wynne, the first Speaker of the Pennsylvania Assemblies had when he treated his patient, William Penn.

Yesterday I saw an inadequately treated Lyme patient with homicidal rage, another with depersonalization and suicidality, and I arranged a brain bank donation for a terminal Lyme dementia case. I get the phone calls when an inadequately treated Lyme patient becomes violent, or shoots up a school, or shoots up a church, or kills a 3-year-old with a hunting knife, or strangles an 11-year-old, or kills their doctor, or kills someone on the highway from narcolepsy from Lyme, or becomes suicidal, or commits suicide or overdoses on opioids, or fails in school, or is paralyzed by panic attacks, or is overwhelmed by their symptoms.

If the politicians who question the value of this legislation would read my journal articles, sit in my office or the office of other doctors who treat these patients and listen to the phone calls, follow me into the prisons when I do an evaluation, sit with me when I talk to grieving family members who have lost a loved one to suicide or a drug overdose and see the human price of this disease, I am sure they would vote yes for HB629.