

CDC Employs Denial to Downplay Lyme Epidemic

I. Introduction

This analysis will demonstrate how the Centers for Disease Control and Prevention (CDC) Lyme policy is founded on denying the complexity and possible severity of Lyme. Denial is used to downplay the both the spread of the epidemic and the seriousness of the disease. By doing so, the CDC fails its own standards for disease surveillance and prevention. The analysis includes a series of comparative reviews that illustrate the peculiar manner whereby the CDC defined the disease. The analysis displays how the CDC employs a set of Lyme treatments that have failed to meet the international standards for evidence-based medicine to stigmatize and scapegoat Lyme patients. The analysis includes an historical perspective of how the CDC has manipulated selective discrimination against particular patient groups to downplay the risks of an epidemic infection.

II. Chronic Lyme Existed in 1991

In January 1991, the CDC published its [official statement on Lyme Disease](#). The publication includes details regarding how the disease is spread, its geographic distribution, the life cycle of Lyme ticks, Lyme in domestic animals, symptoms and signs of [human] Lyme disease, Lyme and pregnancy, diagnosis, treatment and prognosis, prevention, personal protection from tick bites, and Lyme research.ⁱ

This 1991 CDC publication describes the complex, systemic, multi-symptom and sometimes devastating and chronic disease experienced by many Lyme patients. Lyme patients include those who suffer from Lyme, persistent or chronic Lyme, and complications from other tickborne illnesses (TBD). Practitioners who serve this patient community are also familiar with Lyme/TBD as described in the 1991 official CDC statement on Lyme disease. The 1991 CDC publication recognizes:

- persistent Lyme infection,
- the need to orient treatment to the individual case,
- that several antibiotics are effective
- and both oral and IV forms of antibiotics may be useful treatment.

Some illustrative examples from the 1991 CDC Lyme publication follow:

- “In some persons the rash never forms; in some, the first and only sign of Lyme disease is arthritis, and in others, nervous system problems are the only evidence of Lyme disease...

- Lyme disease is often difficult to diagnose because its symptoms and signs mimic those of many other diseases.
- The fever, muscle aches, and fatigue of Lyme disease can easily be mistaken for viral infections, such as influenza or infectious mononucleosis.
- Joint pain can be mistaken for other types of arthritis, such as rheumatoid arthritis, and neurologic signs can mimic those caused by other conditions, such as multiple sclerosis.
- Lyme disease is treated with antibiotics under the supervision of a physician. Several antibiotics are effective.
- **Varying degrees of permanent damage to joints or the nervous system can develop in patients with late chronic Lyme disease. Typically, these are patients in whom Lyme disease was unrecognized in the early stages or for whom the initial treatment was unsuccessful.**
- **Antibiotics usually are given by mouth but may be given intravenously in more severe cases.**
- **In a few patients who are treated for Lyme disease, symptoms of persisting infection may continue or recur, making additional antibiotic treatment necessary.**
- Rare deaths from Lyme disease have been reported.
- ...Lyme disease acquired during pregnancy may lead to infection of the fetus and possibly to stillbirth.”

In this 1991 CDC publication, the CDC listed a number of key areas for research. They included:

- “Effects of mother's infection on the developing fetus.
- How Lyme disease bacteria cause chronic infections of the joints and nervous system and how to prevent these complications.”

After 1991, the CDC erased chronic Lyme infection from their depiction of the disease and began to minimize the range and severity of the symptoms. The CDC denial of persistent Lyme infection has been many times disproven. There are more than [700 peer reviewed articles](#) that support the evidence of persistence of Lyme and certain TBD.ⁱⁱ Recently, Kim Lewis, PhD, of Northeastern University, reported on viable Lyme persister cells which survive and thrive in the laboratory after antibiotic treatment during the 2015 annual Lyme disease conference at Massachusetts General Hospital in Boston.ⁱⁱⁱ During this same conference, Linden Hu, MD, of Tufts University/New England Medical Center, presented findings from a recent xenodiagnoses study detailing evidence of Lyme infection in humans previously treated with antibiotics.

III. CDC Applies Peculiar Practices for Lyme Case Definition

III.1. Lyme is Defined for Surveillance

The 1990 [Case Definitions for Public Health Surveillance](#) guide was a collaborative effort between the CDC and the Council of State and Territorial Epidemiologists (CSTE). The guide was developed to nationally standardize health surveillance data.^{iv}

According to the CDC, “a case definition is a set of uniform criteria used to define a disease for public health surveillance. Case definitions enable public health to classify and count cases consistently across reporting jurisdictions, and should not be used by healthcare providers to determine how to meet an individual patient’s health needs.”^v

1990 CDC/CSTE Case Definitions were developed for 55 conditions including Lyme and Acquired Immunodeficiency Syndrome (AIDS), Amebiasis, Anthrax, Aseptic Meningitis, Botulism, Brucellosis, Chancroid, Chlamydia trachomatis Infection, Cholera, Dengue Fever, Diphtheria, Encephalitis, Foodborne Disease Outbreak, Genital Herpes, Genital Warts, Giardiasis, Gonorrhea, Granuloma Inguinale, Haemophilus influenza, Hansen Disease, Hepatitis, Kawasaki Syndrome, Legionellosis (Legionnaire's Disease), Leptospirosis, Listeriosis, Lymphogranuloma Venereum Infection, Malaria, Measles, Meningococcal Disease, Mucopurulent Cervicitis, Mumps, Nongonococcal Urethritis, Pelvic Inflammatory Disease, Pertussis, Plague, Poliomyelitis, Psittacosis, Rabies, Reye Syndrome, Rheumatic Fever, Rocky Mountain Spotted Fever, Rubella, Salmonellosis, Shigellosis, Spinal Cord Injury, Syphilis, Tetanus, Toxic Shock Syndrome, Trichinosis, Tuberculosis, Tularemia, Varicella (Chickenpox) Waterborne Disease Outbreak and Yellow Fever.

Prior to the presentation of the new case definitions, the 1990 CDC/CSTE guide stated core principles that define CDC’s standards for surveillance. “Surveillance demands uniformity, simplicity, and brevity. These case definitions are intended to establish uniform criteria for disease reporting...*they should not be:*

- used as sole criteria for establishing clinical diagnoses,
- determining the standard of care necessary for a particular patient,
- setting guidelines for quality assurance, providing standards for reimbursement, or
- initiating public health actions.”^{vi}

Out of these 55 health conditions, **only the Lyme case definition included a restatement of a core surveillance principle**, “This surveillance case definition was developed for national reporting of Lyme disease; it is NOT appropriate for clinical diagnosis.”

III.2. Random Lyme Symptom Selected to Represent the Disease

There are clear differences between the clinical description of Lyme and the case definition of Lyme. For example, the 1990 case definition states ‘The best clinical marker for the disease is the initial skin lesion...’ whereas the 1991 [Symptoms and signs of \[human\] Lyme disease](#) states, “In some persons the rash never forms; in some, the first and only sign of Lyme disease is arthritis, and in others, nervous system problems are the only evidence of Lyme disease.”

A review of a number of Lyme studies written between 1981 and 1991 found most experts described Lyme as ‘a systemic, tick-borne disease with protean or wide ranging manifestations, including dermatologic, rheumatologic, neurologic, and cardiac abnormalities’. The literature review showed no consensus that “the best clinical marker for the disease is the initial skin

lesion.” This lack of consensus may explain why the 1990 CDC/CSTE publication added the additional warning for Lyme... “This surveillance case definition was developed for national reporting of Lyme disease; it is NOT appropriate for clinical diagnosis.”

In addition, most Lyme experts agreed with [William Burgdorfer’s 1991 study](#) that Lyme generated a wide range of systemic manifestations.^{vii} William Burgdorfer is the world famous scientist who discovered the borrelia pathogen causing illness in Lyme, Connecticut. The Lyme borrelia was named in his honor ‘Borrelia burgdorferi.’ According to Burgdorfer, since 1981 Lyme acquired a ‘steadily increasing clinical spectrum’ including:

- “erythema migrans (skin lesion or rash)
- acrodermatitis chronica atrophicans (a chronically progressive dermatological condition that leads to widespread atrophy of the skin with damage to the peripheral nervous system)
- lymphadenosis benigna cutis (a group of benign skin disorders, eruptions and growths)
- arthritis
- myocarditis (an inflammation of the middle layer of the heart wall affecting both the heart's muscle cells and the heart's electrical system, leading to reduction in the heart's pumping function and to irregular heart rhythms)
- progressive meningoencephalitis (increasing inflammation of the brain and the three casings surrounding the brain)
- myositis (inflammation and degeneration of muscle tissue)
- and various eye and skin disorders.”^{viii}

III.3. Unlike Others, Lyme Case Definition is Stagnant

The 1990 [Case Definitions](#) Guide stated another core principle of surveillance, “As knowledge increases and diagnostic technology improves, some definitions will change to reflect those trends.” This analysis reviewed 30 diseases’ case definitions to determine if new medical and scientific knowledge and diagnostic tests were incorporated into case definitions between 1990 and August 2016.^{ix} This group of disease includes a wide range of infectious disease, including other vectorborne illness, and bacterial and viral infections.^x

This ‘30 disease case definition review 1990 to 2016’ found:

- Overall, most diseases’ case definitions were revised to include new disease knowledge and many added new diagnostic options for confirmation.^{xi}
- For 26 years, the Lyme case definition has proved to be the clear exception to this practice.

For example, both Lyme and Syphilis are spirochetal diseases with stages of infection including, early, late disseminated and latent of unknown duration. Both Syphilis and Lyme have neurological damage associated with disseminated disease. Both diseases have confirmed association to fetal infection and stillbirths. However, *unlike Lyme*, the Syphilis case definitions of [1990](#), [1996](#) and [2014](#) evolved to add new symptoms and laboratory confirmation options.^{xii}

Another example is the vectorborne Arboviral diseases. The [2004 Case Definitions for the Arboviral](#) diseases identified the following Subtypes: California Serogroup Virus Diseases, Chikungunya Virus Disease, Eastern Equine Encephalitis Virus Disease, Powassan Virus Disease, St. Louis Encephalitis Virus Disease, West Nile Virus Disease and Western Equine Encephalitis Virus Disease. ^{xiii}

The knowledge of Arboviral diseases has expanded over time and a good portion of this knowledge has been incorporated into the [2015 Case Definition for Arboviral](#) diseases. Six California serogroup viruses were added to the case definition (California encephalitis, Jamestown Canyon, Keystone, La Crosse, Snowshoe hare and Trivittatus viruses). An acknowledgement that there are many more arboviruses causing human disease was incorporated, “There are than 130 arboviruses are known to cause human disease. Most arboviruses of public health importance belong to one of three virus genera: Flavivirus, Alphavirus, and Orthobunyavirus.” ^{xiv}

Between 1990 and 2011, there have been four Lyme case definition updates. During this period of time, there has been a significant increase in information relevant for both surveillance and clinical descriptions. However, *unlike most case definitions reviewed*, as well as the Syphilis and Arboviruses examples, this Lyme information has been largely excluded.

For example, Lyme is caused by a bacteria group known as Borrelia. Borrelia are spirochetes. There are increasing numbers of Borrelia found in the USA that are linked to Lyme-like illnesses and not captured by the two-tiered laboratory Lyme diagnostic tests. These include Borrelia bissettii, Borrelia Americana, Borrelia andersonii, Borrelia lonestari, Borrelia miyamotoi, Borrelia turicatae, and Borrelia mayonii; all of which have been confirmed in the USA. ^{xv}

Furthermore, there is recognition that certain knowledge gaps might impact Lyme surveillance, e.g. different strains of Borrelia burgdorferi (Bb) that cause Lyme and more severe symptoms are largely missing from the case definition and clinical description. To note, an April 2001 study on Lyme in the Southern US and published in the [Journal of Clinical Microbiology \(JCM\)](#) found there are two groups of Bb strains from North America that may be involved in human illness on the basis of their genetic similarities to strains from nine patients with disseminated Lyme in Slovenia.

According to the study “the clinical presentations of the Slovenian patients varied, from some patients having a relatively benign illness to some being severely affected. Moreover, some patients had variable and unpredictable serologic responses, including an apparent lack of an antibody response despite disseminated disease.” Similarly, every year there are many thousands of US patients with Lyme symptoms that lack an antibody response to the two-tiered Lyme test. However, such possible explanations for negative test results while showing Lyme symptoms has been ignored. ^{xvi}

Furthermore, there is a lack of new data regarding vector sources and Lyme. For example, according to this 2001 publication, there are fifty-six strains of *Borrelia burgdorferi* (able to interbreed) that have been isolated from ticks and vertebrate animals in Missouri, South Carolina, Georgia, Florida, and Texas. The study confirmed three different tick species carry certain *Borrelia*. They are *Ixodes dentatus*, *Ixodes scapularis* (deer tick or blacklegged tick) and *Ixodes affinis*.

According to the study, “*B. burgdorferi* [sensu strictu or strictly defined] is the dominant genospecies in the northern United States and also occurs in the western and southern areas of the country. *B. andersonii* occurs in the eastern half of the United States. *B. bissettii* occurs in the western and southern United States but rarely occurs in the northern region. It appears to be maintained in several enzootic transmission cycles in California and the southeastern United States and involves several tick species, including human-biting *Ixodes pacificus* ticks in the western half of the United States and *I. scapularis* ticks in the eastern half of the United States.”

In this case, roughly 95 percent of the 2001 information detailed has been excluded from the Lyme case definitions, clinical descriptions and related background found under the CDC ‘[Lyme disease home](#)’.^{xvii} Furthermore, this is but one of many examples of the advances in Lyme science and medical knowledge that have been ignored and denied.

Overall, the Lyme case definition has remained largely stagnant and is always paired with the following statement, “This surveillance case definition was developed for national reporting of Lyme disease; it is not appropriate for clinical diagnosis.”

Furthermore, this caveat is the lead statement in the 2008 and 2011 case definitions of Lyme. In addition, most references used to support the Lyme case definitions and clinical descriptions are sourced from a handful of authors who tend to cite each other.

IV. Response to Lyme Symptoms Starkly Different from Other Diseases

In addition to the case definition reviews comparing Lyme to other illnesses, this analysis includes a more in-depth comparison between Lyme and two diseases that share a similar profile to Lyme. These similarities are (1) the illness ranges from mild, to severe illness and death; and (2) the illnesses have a variety of patient-centered treatment options.

The first example compares Lyme to another tick borne illness, Rocky Mountain spotted fever (RMSF) and the second compares Lyme to Q fever. The information in the RMSF comparison is drawn from the CDC ‘[RMSF home page](#)’ website.^{xviii}

IV.1. Rocky Mountain Spotted Fever and Lyme

RMSF is caused by a rickettsia (a microbe that differs somewhat from bacteria and virus) but often referred to as a bacterium. Unlike Lyme, the case definition for RMSF has been regularly updated and expanded from 1990 to 2010, with four revisions in total.^{xix xx}

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As with Lyme, the CDC notes that Rocky Mountain spotted fever (RMSF) disease is found in many countries. Unlike Lyme, the RMSF vector information and symptomology has been routinely updated and expanded over time. According to the CDC, RMSF is transmitted to humans by several tick species in the US with four that predominate. The CDC website has not included all the tick species that carry Lyme.

As with Lyme, the “early signs and symptoms of RMSF is notoriously nonspecific, or it might mimic benign viral illnesses, making diagnosis difficult.” The CDC warns that the lack of a specific initial RMSF symptoms does not imply that the course of the disease will be benign. Lyme can quickly move beyond a benign presentation to meningitis and cardiac complications, However, for Lyme, the CDC gives no similar warning message to the reader.

According to the CDC, the earlier the RMSF patients seek care in the course of their illness, the more likely an alternate diagnosis will be made... even in RMSF endemic areas. Many Lyme patients have this same experience, however, the CDC does not note this fact for Lyme patients.

Like Lyme, the challenge to clinicians is diagnosing RMSF infections early, when antibiotic therapy is most effective...this is challenging because of test limitations and the range of symptoms. However, the CDC indicates that many persons who appear to have Lyme probably do not have Lyme and that they should not even be tested for Lyme unless they have very particular symptoms.

For RMSF, CDC recommends a “thorough clinical history that elicits recent tick exposure” ...and then elaborates possible scenarios such as “specific recreational or occupational exposures to tick-infested habitats, recent travel to areas where RMSF might be endemic, or similar illnesses in family members, coworkers, or pet dogs can provide critical information that can be used to make a presumptive diagnosis of RMSF.” The CDC goes on to emphasize that the absence of certain features *does not exclude a diagnosis of RMSF*.

For Lyme, CDC makes some similar statements with significant exclusions. There is no mention of considering a ‘similar illness in family members, coworkers, or pet (even in endemic areas) and the CDC does not state that the absence of certain symptoms - such as the ‘Lyme rash’ - *does not exclude a diagnosis of Lyme*.

For both Lyme and RMSF, the CDC acknowledges that most humans are infected through the bites of immature ticks called nymphs. Nymphs are tiny, roughly the size of a poppy seed and difficult to see.

The CDC acknowledges that certain RMSF “patients do not specifically recall tick exposure but might describe other...lesions that they call a mosquito bite, spider bite, chigger bite, or bug

bite, which can be indistinguishable from an actual tick bite.” The CDC indicates such lesions should be a sign of a tick bite and indication of infection.

For Lyme, the CDC acknowledges that it is common for patients to have what looks “a [small bump or redness at the site of a tick bite](#) that occurs immediately and resembles a mosquito bite”. The CDC then goes on to say that a tick bite should not be considered an indication of Lyme. ^{xxi}

With regards to RMSF, the CDC elaborates the many avenues for tick exposure. “A detailed medical history might reveal activities that suggest potential exposure to ticks. Outdoor activities during April--September, particularly in areas with high uncut grass, weeds, and low brush can increase the risk for tick bites. These activities include recreational pursuits (e.g., camping, hiking, fishing, hunting, gardening, and walking dogs) as well as occupational activities that involve persons being in brushy or grassy areas that might be inhabited by ticks.

Vegetation that borders roads, trails, yards, or fields also are potential areas that might be inhabited by ticks. In endemic areas (where the agents causing RMSF are present at all times), even adults or children who play in grassy areas in their backyard are at risk. Queries concerning frequency of contact with family pets, especially dogs, and findings of tick attachment to animals or removal can be useful. The majority of patients will not recall or recognize an attached tick because the location of the tick might be obscure; the bite is typically painless; and bites from smaller immature stages of ticks (e.g., nymphs are approximately 1--2 mm or the size of the head of a pin;) might not be readily detected but might still result in infection. A specific history of a tick bite within 14 days of illness onset is typically only reported in 60% of RMSF cases. **Therefore, the absence of definite tick attachment should never dissuade a physician from considering the diagnosis of a RMSF.”**

Information on the CDC webpage for Lyme transmission is paltry by comparison. It notes that one can contract Lyme from both adult and nymph ticks - more so in certain seasons - and that the ticks are sometimes hard to find on the body.

Unlike the RMSF information, the Lyme information emphasizes that just because you were bitten by a tick and have what could be Lyme symptoms, it does not mean you have Lyme.

The CDC states that starting antibiotics based on the suspicion of RMSF infection will reduce the chances of severe illness and death in otherwise healthy adults and children. The CDC does not state that starting antibiotics based on the suspicion of Lyme infection will reduce the chances of severe illness and death in otherwise healthy adults and children, even though this is most certainly true.

The CDC recommends that “antibiotic treatment should be initiated immediately when a clinician suspects that the diagnosis could be RMSF infection - **based on clinical, laboratory, or epidemiologic findings...**[as] delay in treatment can lead to severe disease and fatal outcome.”

Delayed treatment for Lyme can lead to severe disease and fatal outcome. However, with Lyme, the CDC notes that a number of common Lyme symptoms can indicate other diseases and indicates - even if there was tick exposure – that the healthcare provider should ‘have an observation period’ to avoid misdiagnosis. The CDC also recommends a confirmation by laboratory tests - even though these tests have significant limitations and common false negative results - prior to treatment.

IV.2. Q Fever and Lyme

The next comparison is between Q fever and Lyme. The information is drawn from the CDC website’s ‘disease home pages’ and case definition pages. Both Lyme and Q fever are bacterial infections. Q fever is caused by the bacteria Coxiella.

Between 1999 and 2009, the Q fever case definition added more laboratory confirmation options and more symptoms.^{xxii} The symptoms added to Q fever included “Fatigue, night-sweats, dyspnea, confusion, nausea, diarrhea, abdominal pain, vomiting, non-productive cough, and chest pain have also been reported” and “Pregnant women are at risk for fetal death and abortion.” Furthermore, over time, the CDC has added information to the [Q Fever symptoms, diagnosis and treatment](#) .^{xxiii}

As with Lyme, “Q fever can cause acute or chronic illness in humans.” Like Lyme, Q fever has “a list of symptoms commonly seen” and “the combination of symptoms varies greatly from person to person.” However, unlike for the Lyme reader, the CDC informs the Q fever reader of the many details of such complicating factors.

Like Lyme, “most persons with Q fever recover, others may experience serious illness with complications...[including] myocarditis (inflammation of the heart tissue) and central nervous system complications”. Like chronic Lyme, chronic Q fever is a severe disease occurring in [a percentage of]... infected patients. Like chronic Lyme, the chronic Q disease may present after an acute infection, or may manifest years later. Like Lyme, Q fever endocarditis can indicate a chronic form of the disease. “Patients with [Q fever] endocarditis requires early diagnosis and long-term antibiotic treatment (at least 18 months) for a successful outcome”.

Both Lyme and Q fever share this profile of symptoms and complications, however, they are not elaborated to anywhere near the same degree on the Lyme resource pages. Furthermore, the CDC makes distinctly different recommendations regarding how these bacterial complications should be treated. For example, “Patients with [Q fever] endocarditis requires early diagnosis and long-term antibiotic treatment (at least 18 months) for a successful outcome”. **Unlike Q fever, the CDC recommends a short term of antibiotics for patients with Lyme endocarditis...**

or no antibiotics should this heart complication occur after an initial antibiotic treatment for Lyme.

Like Lyme bacteria, the Q fever bacteria “has the ability to persist for long periods of time in the host after infection.” Like Lyme, this persistent Q infection may include the following symptoms “constant or recurring fatigue, night sweats, severe headaches, photophobia (eye sensitivity to light), pain in muscles and joints, mood changes, and difficulty sleeping.”

Like Lyme, “There are several aspects of Q fever that make it challenging for healthcare providers to diagnose and treat. The symptoms vary from patient to patient and can be difficult to distinguish from other diseases.”

The CDC acknowledges that Q fever diagnostic tests, like Lyme diagnostic tests, have a series of limitations. The CDC recommends that because of Q test limitations, “healthcare providers must use their judgment to treat patients based on clinical suspicion alone.” Furthermore, the CDC recommends “suspect diagnosis of Q fever is made based on signs and symptoms and a high index of clinical suspicion... Treatment should never be delayed pending the receipt of laboratory test results, or be withheld on the basis of an initial negative laboratory result.”

The CDC recognizes that the PCR also has accuracy issues regarding Q fever. According to the CDC, “Although a positive PCR result is helpful, a negative result does not rule out the diagnosis, and treatment should not be withheld due to a negative result.” The CDC has indicated that a PCR test might have accuracy issues with regards to Lyme. *However, in the case of Lyme the CDC suggests withholding treatment based upon a positive PCR.*

The CDC acknowledges that Lyme is a clinical diagnosis and then counters such statements by indicating that the case definition of Lyme describes those symptoms and that it is preferable to have laboratory confirmation prior to starting treatment. The CDC recommends that practitioners use the two-tiered Lyme surveillance test for confirmation. The surveillance test is highly inaccurate, with a possible **50 percent of outcomes being false negatives.**^{xxiv} False negative test results often lead to delayed diagnosis and full systemic complications. These may include serious heart, nervous system and immune impairments, organ dysfunction, life-altering damage and death.

V. Lyme Surveillance Criteria Repeatedly Found Inaccurate

In 1990 the Lyme rash was reviewed for its usefulness as surveillance criteria by the [Connecticut Department of Health \(CDHS\) 1990](#). Of the total Lyme case reports received by CDHS in 1990, 45 percent were based on reports of the rash alone. However, of all the Lyme rashes initially reported, only 65 percent met the criteria of 2+ inches in size. All reporting doctors were then telephoned by researchers to determine if there had been other 2+ inch rashes that may have been missed. This follow up effort resulted in adding additional cases to the surveillance data. However, even with these additions, the introduction of the new 2+ inch

size rash reduced, by 15 percent, the Lyme cases reported that year compared to the previous year. Furthermore, follow up telephone contact was not required following the test year. ^{xxv}

A 1994 Maryland review of Lyme surveillance found “preliminary data suggests that Lyme may be diagnosed by Maryland physicians more frequently than syphilis and tuberculosis. **The data also indicate Lyme is a much larger problem in Maryland than suggested by official reports to the Centers for Disease Control.** ^{xxvi}

A 1994 California study on Lyme surveillance found:

- 166 patients presented with disseminated late Lyme disease symptoms
- 115 of the 166 patients had nonspecific symptoms including joint pain, muscle pain, fatigue, abnormal sensations (tingling, pricking, etc.) and confusion, depression, or both
- **90 of the 166 patients tested positive for Lyme**
- **Only 34 of 166 met the national surveillance case criteria for Lyme disease**
- Many suspected cases of Lyme disease in this endemic area do not meet surveillance criteria ^{xxvii}

[A 1995 CDC publication on Lyme surveillance](#) noted “Ascertainment of LD cases based only on passive surveillance may result in underreporting of cases.” ^{xxviii}

Therefore, it was not surprising when an [August 2013 CDC Press Release](#) announced that Lyme was underreported by as much as tenfold. “According to the CDC, the number of Americans diagnosed with Lyme disease each year is around 300,000 as opposed to 30,000. “This new estimate supports studies published in the 1990s...”

“We know that routine surveillance only gives us part of the picture, and that the true number of illnesses is much greater,” said Paul Mead...chief of epidemiology and surveillance for CDC’s Lyme disease program. “This new preliminary estimate confirms that Lyme disease is a tremendous public health problem in the United States...”^{xxix}

In this case, the CDC has authority to revise the case definition in order to improve surveillance accuracy. Furthermore, the CDC has routinely updated the case definitions for many illnesses under surveillance. However, the low accuracy noted in numerous Lyme surveillance studies from the 1990s and the 2013 study did not result in the CDC changing the Lyme case definition.

VI. CDC Redefines Lyme and Creates Syndrome

Rather than change the case definition for Lyme, the CDC has massaged its clinical description of Lyme to harmonize with a case definition that captures one tenth or less of those infected with Lyme. Part of this revision has focused on how to treat the disease.

As previously noted, both Q fever and RMSF share a wide range of symptoms with Lyme. The CDC states Q fever and RMSF often require longer-term antibiotic treatment for the such

patients, e.g. **at least 18 months for Q fever endocarditis**. In addition to these two illness, there are many other diseases that share Lyme's more serious symptoms and are treated until such symptoms resolve.

For example, both Coccidioidomycosis or Valley Fever (VF) and Lyme manifest infection in a range of ways - from light symptoms to serious complications and death. Both illnesses can be contracted by anyone who has any contact with the natural environment. Both illnesses can be difficult to diagnose. Both VF and Lyme can generate lifelong debilitation and require lifelong treatments. Both VF and Lyme can have persistent and debilitating symptoms. However, the CDC provides starkly different treatment pathways for VF patients versus the Lyme patients.

According to the CDC's [How is Valley Fever treated](#), there are range of treatment options that correspond with the range and seriousness of the VF symptoms and disease. According to the CDC, "For many people, the symptoms of Valley Fever will go away within a few months without any treatment. Healthcare providers choose to prescribe antifungal medication for some people to try to reduce the severity of symptoms or prevent the infection from getting worse...People who have severe lung infections or infections that have spread to other parts of the body always need antifungal treatment and may need to stay in the hospital. For these types of infections, the course of treatment is usually longer than 6 months. Valley Fever that develops into meningitis is fatal if it's not treated, so lifelong antifungal treatment is necessary for those cases." ^{xxx} Many late stage Lyme patients also develop meningitis.

Unlike most diseases with similar serious symptoms, the CDC states that such Lyme symptoms should resolve with 10 days to 4 weeks of antibiotics. These recommendations are derived from Guidelines that have failed both federal and international standards for evidence based medicine. ^{xxxi} The CDC ignores the Lyme treatment recommended in the Guidelines that meet all the evidence based standards. ^{xxxii} The CDC goes on to state that those patients whose symptoms do not resolve after this short term treatment must have a syndrome and suggest it is linked to a form of previously unrecognized mental illness.

Here follow the Lyme symptoms the CDC states should resolve with 10 days to 4 weeks of antibiotics: fever, chills, headaches, fatigue, muscle and joint aches, swollen lymph nodes, severe headaches and neck stiffness, rashes, arthritis with severe joint pain and swelling (particularly the knees and other large joints), facial or Bell's palsy (loss of muscle tone or droop on one or both sides of the face), intermittent pain in tendons, muscles, joints, and bones, heart palpitations or an irregular heart beat - Lyme carditis that interferes with the normal movement of electrical signals from the heart's upper to lower chambers, a process that coordinates the beating of the heart - the result is something physicians call "heart block," which can be mild, moderate, or severe and can progress rapidly to death, episodes of dizziness or shortness of breath, nerve pain, shooting pains, numbness, or tingling in the hands or feet, problems with short-term memory and inflammation of the brain and spinal cord.

The CDC has taken a number of actions to change the understanding of and response to Lyme. The CDC has created a syndrome to account for those who remain uncured by a treatment protocol that has failed to meet the international standards for evidence based medicine. This syndrome is called the Post Lyme Treatment Syndrome (PLTS). According to the National Institute of Health (NIH), patients with PLTS suffer from a somatic psychiatric condition.

Apparently, both the CDC and NIH believe that Lyme patients who fail to be cured by a short course of antibiotics have this psychiatric condition. In addition, the CDC recommends such patients seek assistance from organizations and practitioners that use antidepressants, steroids and painkillers to manage their symptoms. Such palliative care would mask and inflame a systemic infection.

It should be noted that this syndrome is applied to anyone who takes antibiotic treatment for chronic Lyme; including hard charging billionaire John Caudwell, famous musician Daryl Hall and star athletes such as women's basketball Most Valued Player Delle Donne and Olympic athlete Angeli VanLaanen.

VII. Making it Personal

The process of undertaking and analyzing surveillance data makes use of organizing categories. One of the common categories is that of "person." Such person categories help determine who is at risk of experiencing an undesirable health condition, such as becoming infected with certain bacteria. For example, a person's livelihoods might increase their risk of tickborne illnesses, e.g. a landscaper. For another illness, certain behaviors might increase their risk of exposure, e.g. smoking and lung cancer. 'Person categories' might include 'inherent characteristics' such as age, race, sex, 'acquired characteristics' such as immune health, financial status, and activities such as occupation, leisure activities, use of medications and illegal drugs. ^{xxxiii}

When medical and scientific researchers and practitioners find persons with a particular characteristic are more likely than those without the characteristic to develop a certain disease, then the characteristic is said to be associated with the disease. The 'associated characteristics' factors may include:

- demographic - race, age, gender
- behavioral - smoking, alcohol use
- circumstantial - home built on old dump site, or
- constitutional - Blood group

For example, a good portion of the American public was very concerned when AIDS was 'discovered' and described as being sexually transmitted. This wide spread concern was reduced when the CDC postulated that AIDS was a result of "the homosexual lifestyle". In this case, being a homosexual was considered a characteristic associated with AIDS.

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However, it was soon clear that AIDS was found in other groups of people that included heterosexuals. Heterosexual transmission of AIDS was again very concerning to the American public. This concern was rather diverted when [the CDC published](#) the following statement “most cases of AIDS have been reported among homosexual men with multiple sexual partners, people who inject drugs, Haitians, and hemophiliacs.”^{xxxiv}

Public response to this scapegoating included mocking the CDC policy as the ‘4H Club’. Of course, the four groups of people now “associated” with AIDS found this CDC statement to be a political exercise that stigmatized and scapegoated rather than a scientific analysis that served AIDS patients or helped to prevent the spread of the AIDS epidemic.

There were number of public meetings, media events and publications that expressed outrage at the CDC’s tactics to focus fear on groups of people, including the Baltimore Afro-American newspaper December 18, 1982 article [“Epidemic hits Homosexuals, Haitians, Hemophiliacs and Heroin users - 4H Alert!”](#)^{xxxv}

While the CDC stigmatized and scapegoated the 4H Club, there was recognition in certain branches of government that a virus was unlikely to forgo an infection opportunity according to passports or sexual preference. In 1985, the Pentagon announced all new military recruits were to be tested for HIV infection and those who test positive for the virus would be rejected. What was not publicized was that the military was already discharging active members who tested positive.

In the 1980s, AID activists knew many with AIDS were not diagnosed as such because of the restricted AIDS case definition. They promoted a series of public awareness campaigns including [“women don’t get AIDS, they just die from it.”](#) The message included the following information about the AIDS case definition, “65% of HIV positive women get sick and die from chronic infections that don’t fit the Center for Disease Control’s definition of AIDS. Without that recognition women are denied access to what little health care exists. The CDC must expand the definition of AIDS.”^{xxxvi}

It wasn’t until 1993, in response to increasing public and political pressure, that the CDC expanded the case definition of AIDS to include those with CD4 counts below 200 and three new conditions. This expanded case definition meant that many more women would be diagnosed with AIDS and therefore access treatment for AIDS.

Today, the AIDS case definition has been expanded to include more than 60 opportunistic infections that indicate the presence of the virus. Every time the case definition has expanded, more of those with the virus have gained access to treatment. Furthermore, there has been an increase in the range of AIDS treatment options.

CDC Employs Denial to Downplay Lyme Epidemic

By Jenna Luché-Thayer
August 22, 2016

The CDC policy to stigmatize and scapegoat homosexuals, Haitians, hemophiliacs and heroin users was crude, ugly and incredibly ineffective. Many persons who did not fall into the 4H Club believed themselves to be of little risk for AIDS infection. They therefore did not change behaviors and so the epidemic continued to grow across all sectors of society and reach into every corner of the nation. Over time, the CDC AIDS policy has become more competent. Today, all health departments have posters that state if anyone has had sex with five or more persons that person is at risk for AIDS.

The CDC response to the Lyme epidemic echoes the ugly and incompetent response witnessed during the first 15 years of the AIDS epidemic. As did the AIDS case definition deliberately exclude many of those with AIDS, so does the Lyme case definition exclude many Lyme patients, including those with severe debilitations and systemic damage, persistent Lyme infection and TBD complications.

For 25 years, there has been great awareness that the Lyme case definition is problematic on numerous fronts. For example, the [2001 107–84 Congressional Report](#) regarding the Departments of Labor, Health and Human Services and Education Appropriations Bill stated,

“The Committee recognizes that the current state of laboratory testing for Lyme disease is very poor. The situation has led many people to be misdiagnosed and delayed proper treatment...The ramifications of this deficit in terms of unnecessary pain, suffering and cost is staggering.”

“The Committee directs CDC to work closely with the Food and Drug Administration to develop an unequivocal test for Lyme disease.”

“The Committee is distressed in hearing of the widespread misuse of the current Lyme disease surveillance case definition...the definition is reportedly misused as a standard of care for healthcare reimbursement, product (test) development, medical licensing hearings, and other legal cases.”

“The CDC is encouraged to aggressively pursue and correct the misuse of this definition. This includes issuing an alert to the public and physicians, as well as actively issuing letters to places misusing this definition.”

“The Committee recommends that the CDC strongly support the re-examination and broadening of the Lyme disease surveillance case definition...Voluntary and patient groups should have input into this process.”

However, the CDC has not responded to this 2001 request and many more congressional requests stating the same concerns. Furthermore, the CSTE position paper for the 2011 Lyme case definition clearly stated that the two-tiered Lyme test was to be used for surveillance

purposes only, it was not for clinical diagnosis. Since 1990, the CSTE has repeatedly stated the case definition symptoms were not to be used for clinical diagnosis.

Despite these recommendations and the unchecked spread of the epidemic, the CDC has conflated the case definition and the corresponding two-tiered Lyme test with the clinical description and guidelines for diagnosis. Such actions are in direct violation of the CDC's own stated practices and core principles for surveillance that case definitions *should not be* used as sole criteria for establishing clinical diagnoses nor should they determine the care for a particular patient. ^{xxxvii}

Reminiscent of the CDC's creation of the 4H club in response to the AIDS epidemic, the CDC Lyme policy has institutionalized stigmatizing and scapegoating of Lyme patients. Such discrimination against Lyme patients diverts attention from CDC's untenable and rather useless Lyme case definition, wasteful surveillance guidance, faulty and misapplied diagnostic tests and spurious guidance for clinical diagnosis and treatment.

In addition to the CDC stigmatizing and scapegoating of Lyme patients, there have been an array of NIH grantees generating articles and studies that contribute to the active discrimination of chronic Lyme/TBD patients. NIH has sponsored studies and articles that misuse the term 'Medically Unexplained Symptoms' when characterizing patients who suffer from persistent Lyme symptoms, chronic Lyme, post Lyme Disease Syndrome and Lyme with complicating coinfections.

The phrase 'Medically Unexplained Symptoms' (MUS) appears to be innocuous. In fact, the term *MUS is considered a psychiatric disorder* found under the Diagnostic and Statistical Manual of Mental Disorders (DSM) category of Somatic Symptom Disorder.

In laymen's terms, persons with MUS suffer from a self-absorbed and exaggerated preoccupation with physical symptoms or a hypochondria that interferes with their ability to be productive and functional.

However, the NIH grantees and officials who apply MUS to Lyme patients have apparently not read the "[the DSM-5](#). DSM-5 cautions "it is not appropriate to diagnose individuals with a mental disorder solely because a medical cause cannot be demonstrated" ^{xxxviii} and "The reliability of medically unexplained symptoms is limited, and grounding a diagnosis on the absence of an explanation is problematic..." ^{xxxix}

NIH grants have sponsored a number of articles that erroneously describe chronic Lyme patients as having MUS. They include:

- 2015 [Chronic Lyme Disease](#) by Paul M. Lantos, MD of Duke University ^{xl}

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- 2014 [Chronic coinfections in patients diagnosed with chronic Lyme disease: a systematic literature review](#) by Paul M. Lantos and Gary P. Wormser, MD of New York Medical College ^{xli}
- 2015 [Unorthodox Alternative Therapies Marketed to Treat Lyme Disease](#) by Paul M. Lantos, MD, Eugene D. Shapiro of Yale University, Paul G. Auwaerter of Johns Hopkins, Phillip J. Baker of American Lyme Disease Foundation, John J. Halperin of Overlook Medical Center NJ and Icahn School of Medicine NY, Edward McSweegan, NIH official and of Global Virus Network, Maryland, and Gary P. Wormser. ^{xlii}

In addition to misusing the term MUS, the 'Alternative Therapies' article appears to have supported a 'study' based on an internet search that linked 'Lyme to alternative treatments'. ^{xliii} [Lead author Lantos of Duke](#) is quoted as saying "While we did not have a way to show how frequently patients with Lyme disease pursue these treatments, we felt it was important that doctors treating them be aware that they are specifically targeted by a very diverse array of therapies." ^{xliii} Lantos would be able to make the same absurd pronouncement for an internet search that linked 'cancer to alternative treatments'. The 'Alternative Therapies' article was supported with \$9,664,484M in NIH grants.

Not only do these three articles misapply the psychiatric term MUS to patients suffering from serious and life threatening Lyme complications, they also fail to meet the basic performance criteria and objectives of the sponsoring NIH grants. None of these articles represent original research or advance knowledge and patient care. These unprofessional lapses are particularly striking given one of the authors is a senior ranking NIH official.

\$11,825,648M, representing another six NIH grants have supported Yale University and the University of Pennsylvania to produce articles and studies that:

- Discredit Lyme patients, advocacy groups and physicians, and invalidate their experience with the disease
- Marginalize the Lyme community and advocates from decision-makers that determine access to care and insurance coverage of Lyme
- Undermine their access to discourse and engagement with scientific and medical communities
- Deny their full rights as citizens to engage as stakeholders with government officials on topics of their deep and valid concern. ^{xliii}

CDC discrimination practices includes the Post Lyme Treatment Syndrome (PLTS). As noted, PLTS is a condition that transforms a Lyme patient into a person who should be treated for MUS rather than a systemic infection.

The CDC's promotion of PLTS may have unintended consequences. Based on information from the CDC report [Incidence of Clinician-Diagnosed Lyme Disease, United States, 2005–2010](#), and

other sources, there are approximately 300,000 cases of Lyme per year.^{xlvi} According to the CDC, approximately twenty percent will fail to be cured and be classified as having PLTS.

Given these numbers, the CDC's recommended treatments for PLTS include exposing potentially 60,000 persons a year to the risk of painkiller addiction. PLTS-linked-MUS has the potential of erroneously adding 60,000 persons per year to the mental illness category. Therefore, since 2005, the CDC Lyme policy has created situations wherein 720,000 patients may be potentially misclassified as mentally ill and increased the risk of addiction for as many as 720,000 people.

Conclusions

The CDC Lyme policy fails its own standards for disease surveillance and prevention. Overall, CDC practices surrounding Lyme case definition, surveillance, clinical guidance, clinical descriptions and treatments guidance stand in stark contrast to other conditions, particularly those illnesses with similar symptoms.

The misapplication of Medically Unexplained Symptoms is an inept and transparent effort to blame patients for treatment failures.

The Post Lyme Treatment Syndrome is a fraudulent term with potentially dangerous and costly consequences.

The CDC has not learned from its botched stigmatizing of certain groups during the AIDS epidemic.

The stigmatizing of certain groups, the arbitrary exclusion of certain patients from diagnosis and treatment, and the under-reporting of the Lyme epidemic will not make it disappear.

Altogether, such practices shine doubt on both the institutional credibility and competence of the CDC and indicate it is a political organization unconcerned with science and public health.

Jenna Luché-Thayer

Founder, Global Network on Institutional Discrimination™
Holding institutions accountable for political and scientific solutions

Jenna Luché-Thayer is a political strategist and advocate working across the globe to help institutions remedy entrenched practices of discrimination that interfere with their higher purpose.

Currently, Luché-Thayer is assisting institutions and communities to:

- Overcome more than 30 years of discriminatory practices against those living with Lyme, chronic Lyme and tickborne diseases (TBD) and
- Build a humane and rights based patient-centered response to the Lyme disease epidemic.

Luché-Thayer's expertise includes government transparency and accountability and the integration of marginalized groups. Luché-Thayer is informed by three decades of professional policy and grassroots experience in 40 countries. She has extensive experience in congressional relations, testimony and legislation. She has worked with governments, the United Nations, nonprofits and the corporate world and has over 65 sponsored publications. Luché-Thayer received the International Woman's Day Award for Exemplary Dedication and Contributions to Improving the Political and Legal Status of Women (US government) and built the Highest Ranking Technical Area in Accomplishment, Innovation & Comparative Advantage for United Nations Capital Development Fund.

ⁱ <http://wonder.cdc.gov/wonder/prevguid/p0000380/p0000380.asp>

ⁱⁱ http://www.ilads.org/ilads_news/wp-content/uploads/2015/09/EvidenceofPersistence-V2.pdf

ⁱⁱⁱ *Borrelia burgdorferi, the Causative Agent of Lyme Disease, forms Treatment-Resistant Persister Cells* by Sharma, B, Brown, A, Matluck, N, Hu, L, Lewis, K, *Antimicrobial Agents and Chemotherapy/ASM.org*, August, 2015, Volume 59, Number 8.

^{iv} <http://wonder.cdc.gov/wonder/prevguid/m0025629/m0025629.asp>

^v <https://wwwn.cdc.gov/nndss/case-definitions.html>

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^x Material for the following diseases was reviewed: Coccidioidomycosis known as Valley Fever, Acute Idiopathic Pulmonary Hemorrhage in Infants, Syphilis, Swine flu, Q fever, West Nile Virus, Hantavirus Pulmonary Syndrome, Ebola, Pertussis, Influenza A (H3N2), Acute Flaccid Myelitis, Diphtheria, HIV/AIDS, MERS (Middle East Respiratory Syndrome), Dengue, Arboviral diseases - neuroinvasive and non-neuroinvasive, Varicella known as Chicken Pox, *Rickettsia rickettsii* or Rocky Mountain spotted fever (RMSF) and Lyme.

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^{xi} A few of the diseases reviewed e.g. MERS, had rather general case definitions intended to capture any possible case of MERS. In these cases, the updates focused on practices related to improved data collection and reporting.

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- ^{xii} <https://wwwn.cdc.gov/nndss/conditions/syphilis/case-definition/1990/>
<https://wwwn.cdc.gov/nndss/conditions/syphilis/case-definition/1996/>
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- ^{xiii} <https://wwwn.cdc.gov/nndss/conditions/arboviral-diseases-neuroinvasive-and-non-neuroinvasive/case-definition/2004/>
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Eglin medical group first to find bacteria unseen in humans By Ilka Cole, Eglin Air Force Base Public Affairs / Published January 13, 2016 see link - <http://www.af.mil/News/ArticleDisplay/tabid/223/Article/642832/eglin-medical-group-first-to-find-bacteria-unseen-in-humans.aspx>
- ^{xvi} <http://jcm.asm.org/content/39/7/2500.full#ref-29>
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- ^{xviii} <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5504a1.htm>
<http://www.cdc.gov/lyme/index.html>
- ^{xix} <https://wwwn.cdc.gov/nndss/conditions/spotted-fever-rickettsiosis/>
<https://wwwn.cdc.gov/nndss/conditions/spotted-fever-rickettsiosis/case-definition/2010/>
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- ^{xxiv} <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2078675/>
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- ^{xxvii} Ley CT, Davila IH, Mayer NM, Murray RA, Rutherford GW, Reingold AL. Lyme disease in northwestern coastal California. *Western J Med* 1994;160:534-9.
- ^{xxviii} <http://wonder.cdc.gov/wonder/prevguid/m0038002/m0038002.asp>
- ^{xxix} <http://www.cdc.gov/media/releases/2013/p0819-lyme-disease.html>
- ^{xxx} <http://www.cdc.gov/fungal/diseases/coccidioidomycosis/treatment.html>
- ^{xxxi} The Infectious Diseases Society of America (IDSA) Lyme Guidelines do not meet the standards set by the Institute of Medicine and Agency for Healthcare Research Criteria and Quality (AHRQ). The Institute of Medicine set the Standards for Developing Trustworthy Clinical Practice Guidelines and the Grading of Recommendations Assessment, Development and Evaluation (GRADE) Working Group system for grading quality of evidence and strength of recommendations. The AHRQ is the lead Federal agency charged with improving the safety and quality of America's health care system. AHRQ develops the knowledge, tools, and data needed to improve the health care system and help Americans, health care professionals, and

policymakers make informed health decisions. The National Guidelines Clearinghouse (NGC) provides summaries regarding evidence-based clinical practice guidelines, their development and implementation. AHRQ sponsors the NGC database and website for information on evidence-based clinical practice guidelines. The IDSA Lyme Guidelines were removed from the NGC website for noncompliance to its criteria and that of the HMD and GRADE.

^{xxxii} The International Lyme and Associated Diseases Society (ILADS) Lyme Treatment Guidelines posted on the National Guideline Clearinghouse Website.

^{xxxiii} Principles of Epidemiology, Second Edition, Written by Richard C. Dicker

^{xxxiv} <https://www.aids.gov/hiv-aids-basics/hiv-aids-101/aids-timeline/>

^{xxxv} <https://news.google.com/newspapers?nid=2205&dat=19821218&id=7PkmAAAAIBAJ&sjid=MAMGAAAAIBAJ&pg=1370,4750215>

^{xxxvi} https://www.publicartfund.org/view/exhibitions/5735_women_dont_get_aids_they_just_die_from_it

^{xxxvii} <http://wonder.cdc.gov/wonder/prevguid/m0025629/m0025629.asp>

^{xxxviii} <http://www.dsm5.org/documents/somatic%20symptom%20disorder%20fact%20sheet.pdf>

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^{xli} <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4252587/>

^{xlii} <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4490322/>

^{xliii} <http://grantome.com/grant/NIH/UL1-TR000142-09>, <http://grantome.com/grant/NIH/KL2-TR000140-09>, <http://grantome.com/grant/NIH/KL2TR001115>

^{xliv} <https://www.dtmi.duke.edu/news/news-duke-ctsa-kl2-scholar-lyme-disease>

^{xlv} May 15, 2016 Analysis held in Congressional review, Misappropriated NIH Grants Marginalize Lyme Patients, by Jenna Luche-Thayer. Copy available upon request from author.

^{xlvi} http://wwwnc.cdc.gov/eid/article/21/9/15-0417_article