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Negotiating the Credibility of Chronic Lyme Disease: Patient Participation in Biomedical Knowledge-Creation

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**NEGOTIATING THE CREDIBILITY OF CHRONIC LYME DISEASE:
PATIENT PARTICIPATION IN BIOMEDICAL KNOWLEDGE-CREATION**

A Thesis Presented
By
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To the keck science department
Of Claremont McKenna, Pitzer, and Scripps colleges
In partial fulfillment of
The degree of Bachelor of Arts

SENIOR THESIS IN HUMAN BIOLOGY

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ABSTRACT

An estimated 300,000 people contract Lyme disease in the USA every year, 10-20% of whom will experience long-term symptoms even after antibiotic treatment. These patients are said to have Chronic Lyme Disease (CLD). However, diagnostic guidelines, treatment protocols, and the etiological existence of CLD have been the subject of much controversy in the biomedical field, leading to negative mental and physical health outcomes for of patients with CLD. Patient support networks focused on illness experience, known as biosocialities, have formed in response to this controversy. CLD biosocialities create opportunities for patients to participate in biomedical activism and the scientific research process. A historical precedent for biosocial impact on biomedical knowledge and improved health outcomes has been established from patient activists with HIV/AIDS, breast cancer, and PTSD. The impact of CLD patients' biosocial activism on a scientific and sociological level is evaluated through an examination of the publications of CLD support networks and biomedical research publications. CLD biosocial activism has resulted in more patient-centered research endeavours, etiological proof of CLD, improved diagnostic technologies, and new treatment protocols. These biomedical results have implications for improved CLD patient health outcomes and credibility for CLD as a legitimate disease on a biological and sociological level.

Keywords: Chronic Lyme Disease, biosociality, biomedical activism

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INTRODUCTION

Extreme fatigue, full-body joint pain, seizures. After months of these severe symptoms, Aaron visits a neurologist in hopes of answers. “That doesn’t make sense,” says the physician in response to Aaron’s symptomology, “perhaps you need to cut down on your caffeine intake.” After 12 months and trips to various other doctors, Aaron is finally diagnosed with Lyme disease and given antibiotic treatment. He dutifully takes the four-week course of pills, but his symptoms remain. Aaron now believes he has Chronic Lyme Disease (CLD) (Jackson, 2018), but his physicians are not so sure. For all intents and purposes, in mainstream biomedicine, CLD does not exist.

Within communities of patients suffering from similar symptoms, there is no doubt of the existence of CLD. From their own phenomenology, patients develop an understanding and definition for their illness. However, patients do not typically have control over the diagnosis and treatments they are able to receive. It is the knowledge and opinions of field of biomedicine, those who control diagnosis and treatment, that truly affect patient care. When there is a clash between the popular understanding and scientific understanding of an illness such as CLD, patients are the ones who ultimately suffer. In response, patients must start to negotiate with scientists and physicians to gain credibility for their illness in an effort to receive new treatment options and improve their health outcomes.

This negotiation of credibility of CLD is especially important in this day and age as the cases of Lyme disease continue to rise in the USA each year (Lantos, 2015). Each year an estimated 300,000 people contract Lyme disease in the continental USA alone, an increased incidence of 300% since the late 1990s according to estimates by the Center for

Disease Control (CDC) (Johnson, Shapiro, et al., 2018; Lantos, 2015; Maloney, 2016). This increase is due in part to the geographic spread of the *Ixodes* tick, which spreads Lyme disease with its bite, transmitting the spirochete bacteria *Borrelia burgdorferi* (*Bb*), the causal agent of the disease (Hsu, Patella, & Sigal, 1993). Lyme disease is normally considered to be a short-term, acute infection and is typically treated with a 10-28 day course of antibiotics such as doxycycline, amoxicillin, or cefuroxime per guidelines set forth by the Infectious Disease Society of America (IDSA) (Auwaerter & Melia, 2012; “Controversies and Challenges,” n.d.; Feng, Shi, Zhang, & Zhang, 2015; Lantos, 2015). Even with treatment, 10-20% of these patients will experience severe symptoms lasting longer than six months in what is dubbed Chronic Lyme Disease (CLD) or Post-Treatment Lyme Disease Syndrome (PTLDS) (Maloney, 2016; Rebman et al., 2017).

Patients with enduring symptoms face the possibility of cardiac complications, chronic pain, insomnia, depression, and neurological symptoms such as a decline in memory function (Lantos, 2015; Rebman et al., 2017; Sigal & Hassett, 2002; Touradji, Aucott, Yang, Rebman, & Bechtold, 2018). When compared to healthy subjects and subjects with prior acute Lyme disease, these patients also report significantly lower “life functioning,” defined as the self-evaluated combination of physical wellness, pain, general health, vitality, social wellbeing, emotional health, and mental health (Aucott, Rebman, Crowder, & Kortte, 2013). Yet, even though an estimated 30,000-60,000 patients are at risk of developing CLD every year, many physicians and scientists in the mainstream biomedical community doubt its existence, leaving patients like Mary unable to receive a diagnosis.

Even if patients suffering from long-term symptomology do receive a diagnosis of PTLDS or CLD, the treatment options are limited after completion of the primary course of

antibiotics. Two meta-analyses of clinical trials found no benefit in treating CLD patients with a second course of antibiotics, and that antibiotic retreatment may actually cause harm to the patients (Klempner et al., 2013; Marques, 2008). It should be noted that many of these retreatment trials have small, highly selective sample sizes, which may vastly skew the research results (Johnson, Shapiro, et al., 2018). In response, within the medical community there is vast disagreement surrounding the success or failure of retreatment found by clinical trials. One 2007 clinical trial, in fact, found potential positive health outcomes upon secondary antibiotic treatment (Raphael B. Stricker, 2007). Additionally, the International Lyme and Associated Diseases Society (ILADS), one of the largest Lyme-focused medical societies, takes the official position that any potential risks associated with antibiotic retreatment are far outweighed by the risk of letting CLD patients go untreated. When patients are given a definitive diagnosis of persistent bacterial infection that constitutes CLD, ILADS recommends they work with their physician to decide if continued antibiotic use is right for them (“ILADS Treatment Guidelines,” n.d.).

However, due to underdeveloped diagnostic technology for Lyme disease, patients often cannot even receive that definitive diagnosis of persistent infection and therefore receive no treatment whatsoever. The standard Lyme disease diagnostic toolkit is a two-tiered test consisting of an Enzyme-Linked Immunoabsorbent Assay (ELISA), which, if positive, is followed by a Western Blot that tests for IgM or IgG immunoglobulin antibodies, representative of extant infection (Rebman, Crowder, Kirkpatrick, & Aucott, 2015; Shah, Cruz, Wronska, Harris, & Harris, 2007). Because these tests do not check for the presence of *Bb*, but rather check for antibodies that may be generated by a number of possible pathogens, a positive serology holds little relevant diagnostic information. It is close to impossible to

tell how long a patient has been infected, whether or not the patient has been *re*-infected, or if the patient has *ever* been infected by *Bb* specifically. These tests also hold a low positive predictive value with a sensitivity estimated at only 44% suggesting that many patients receive false negative lab results (Davidsson, 2018; Lantos, 2015). These misleading lab results, wary of the possibility of *Bb* infection, may prevent patients from receiving needed medical care.

Without ample microbiological proof of sustained post-treatment *Bb* infection, the biomechanism of CLD remains a mystery, with many esteemed researchers completely dismissing the possibility of its existence (Auwaerter *et al.* 2011, Chandra *et al.* 2011). This dismissal has led to what has been dubbed in the Lyme disease community as the “Lyme Wars” (Tonks, 2007), a “battle” between mainstream researchers and the patient advocates who wish to negotiate a higher degree of credibility for the illness, legitimizing its existence to give the ill a better chance at improved health outcomes. As a result of this “war,” troop-like groups of politically driven patients stand at the front lines, actively fighting for the changes they wish to see in CLD research and understanding.

METHODOLOGY

In this thesis, I will utilize the model constructed by Steven Epstein in his book *Impure Science: Aids, Activism, and the Politics of Knowledge* (1996) to evaluate the ways in which the power of activism and social networks centered around Chronic Lyme Disease may be harnessed to combat current controversies surrounding the illness to alter the biomedical knowledge and definition of the illness for improved health outcomes. While the

illness still lacks credibility in the scientific community, successes of CLD biomedical activism have already made great strides in improving patient care.

Epstein utilizes a combination of scientific and medical journals alongside activist documents and publications to “bring into critical juxtaposition contemporaneous records from different ‘social worlds’” of HIV/AIDS (Epstein, 1996). I will briefly evaluate the success of illness activists’ influence on the creation of constitutive biomedical credibility in the context of HIV/AIDS, breast cancer, and mental illness to better understand the current standing of CLD activism’s influence on the biomedical sphere. Like Epstein, I will critically evaluate a number of scientific publications for both their biomedical merit but also for their sociological implications to view them alongside sociological academic documents, narrative accounts of CLD, and the publications of online advocacy networks. I will take a “‘democratic’ approach to claims-making” (Epstein, 1996), giving each of these kinds of publications, regardless of authorship, equal attention and merit in the construction of knowledge. I will build an argument for the cycle of credibility and treatment of CLD depicted below: one in which social networks and activism may feed back to alter the research process or redefine the illness itself (Fig 1). Patient activism will be evaluated on three levels: individual activism, intra-community activism, and activism of CLD communities in biomedical organizations.

The constructed credibility will be understood through the framework suggested by sociologists Collins & Pinch (1979). They have proposed two mechanisms by which credibility is negotiated: constitutive and contingent. 1/29/2019 5:20:00 AM I believe that in negotiating credibility for a disputed illness like CLD, the contingent evidence is equally important and relevant as the constitutive. In fact, I argue that the contingent evidence, the

knowledge held and produced by networks of CLD patients, influences the creation of constitutive, clinical biomedical evidence to produce improved patient health outcomes.

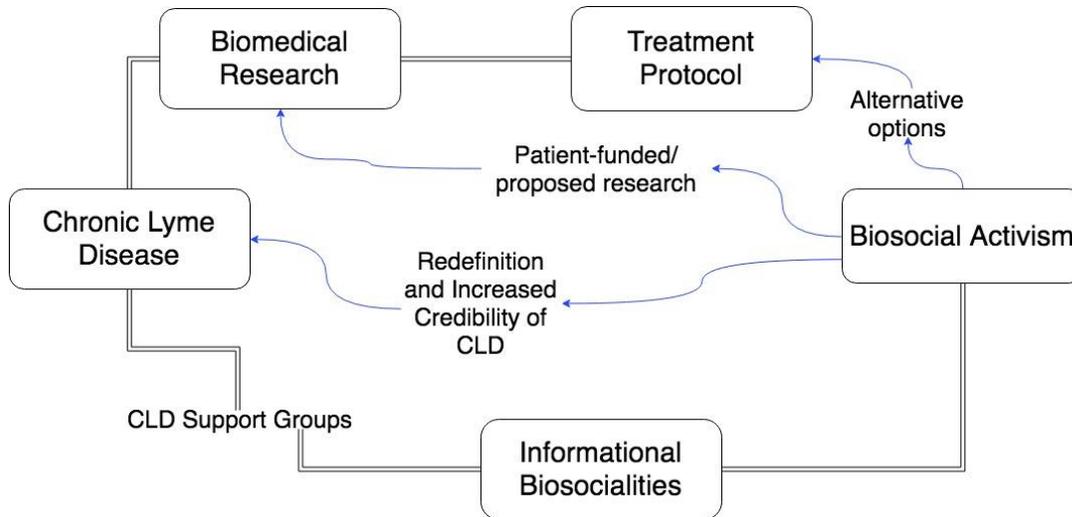


Figure 1. My proposed cycle for the development of biomedical credibility of CLD. Blue arrows indicate patient participation in the knowledge-creation process.

TWO SIDES OF THE “LYME WARS”

The creation of constitutive biomedical knowledge regarding CLD is a constant power struggle between the participants of the “Lyme Wars” (Tonks, 2007). In their seminal text in the field of Science and Technology Studies, *Laboratory Life*, Latour & Woolgar cite the scientist’s laboratory as a site of immense power and influence. In the realm of scientific research, certain professional associations hold a higher degree of power, leading to more funding and publication in more highly-regarded journals, inducing a positive-feedback cycle of credibility, but one in which only a few voices are heard (Latour, Woolgar, & Salk, 1986). Cameron, a former ILADS president, has stated that when evidence in a scientific study is weak, the personal biases and agendas, conscious or unconscious, of the experts on a review panel carry more weight in the perceived constitutive credibility of the study. Cameron, a researcher and fairly biased CLD advocate believes that many of the clinical studies for CLD

produce low quality, difficult to decipher evidence (Cameron, Johnson, & Maloney, 2014) and therefore are more subject to reviewer bias.

With this in mind, and the fact that the highly controversial CLD invokes strong opinions on both sides of the spectrum of experts' agendas, it is imperative to take note of the associations between researchers and their sources of funding in an effort to evaluate the negotiation for credibility of the illness. While each side's goal is ultimately to deliver good science and ensure the best possible patient health outcomes, each camp holds a narrow perspective, which dictates the kinds of studies performed and the interpretation of the results. Auwaerter, a vocal opponent of CLD advocacy, has served as president of the IDSA, which produces a journal in which other CLD opponents such as Marques have been published (Fig. 2). Many CLD advocates have received funding from the Lyme Disease Research Foundation, founded by Aucott, or are associated with funding recipients (Fig. 3). Other researchers have direct ties to ILADS, of which, as noted earlier, Cameron has served as president. Maloney works as part of their education outreach program to train LLMDs. Johnson, associated with many of the ILADS researchers, is the executive director of LymeDisease.org, which, in publishing *Lyme Times*, has circulated opinion pieces by Fallon and other biomedical researchers (Fig 4). While both sides of the "Lyme Wars" deliver novel and valid scientific studies, it is the advocate scientists who will contribute to constitutive credibility necessary to redefine and reevaluate CLD.

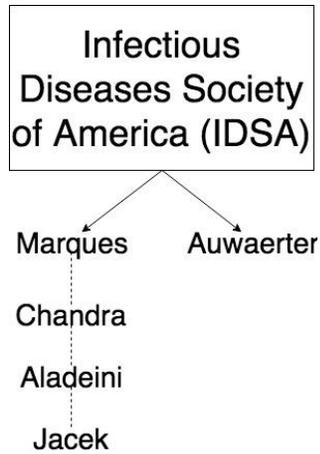


Figure 2. Researcher associations with IDSA, a CLD skeptical group. Arrows indicate direct funding or association. Dotted lines indicate relationships via laboratories.

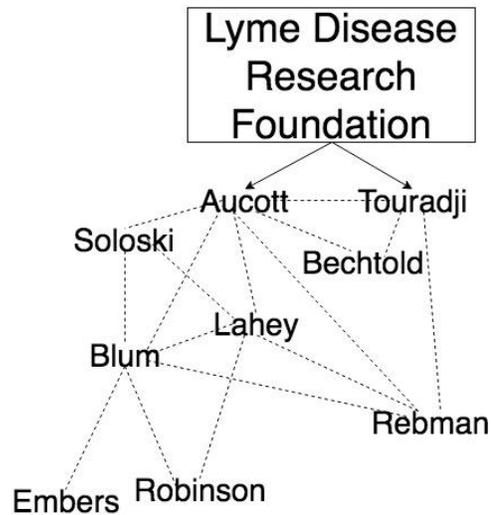


Figure 3. Researcher associations with Lyme Disease Research Foundation, a CLD-advocate group. Arrows indicate direct funding or association. Dotted lines indicate relationships via laboratories.

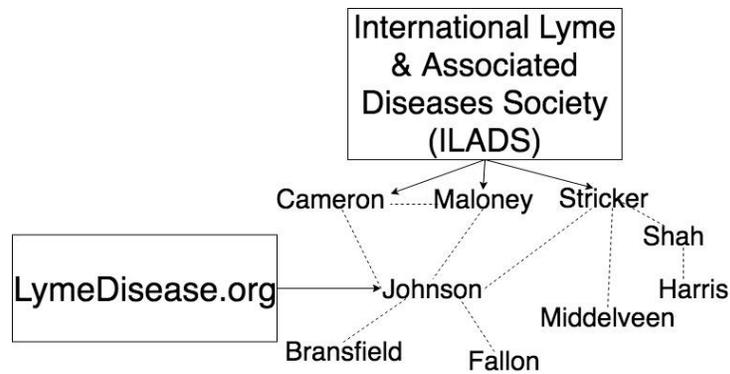


Figure 4. Researcher associations with ILADS and LymeDisease.org, CLD-advocate groups. Arrows indicate direct funding or association. Dotted lines indicate relationships via laboratories or publication.

BIOSOCIALITIES

Many advocate researchers are pushed toward their CLD-positive stance from the encouragement of CLD biosocialities. “Biosocialities,” a term coined by anthropologist Paul Rabinow in 1994, are identity-based support networks developed around “corporeal vulnerability,” the state of precarity of the body endangered by illness, and “somatic suffering,” the phenomenology of experienced illness (Rose & Novas, 2002). When experiencing a chronic illness, many suffers may redefine their personal identity and illness experience as their illness changes their day to day life functioning, inserting itself into the patient’s life plan (Brown, 1995). For the chronically ill, there may be no distinction between the internalized personal identity, the physical state of the body, and the illness itself; the phenomenon of illness is, in itself, a subject, “the very grounds of subjectivity or experience in the world” (Good, 1994), which lends itself to search for an affinitive community. Through these communities of shared phenomenological experience, a patient may find empowerment and legitimizing contingent credibility for their illness.

Biosocialities of CLD patients, which I will show are capable of developing contingent and

later constitutive credibility for their illness, are built out of solidarity in direct response to the discrediting and confusing controversy of the “Lyme Wars.”

BACKGROUND

THE CHRONIC LYME CONTROVERSY

At the root of the CLD controversy is the fact while a great deal of research has been performed to uncover the etiology of CLD, the results of most studies published in highly reputable scientific journals like *The Lancet* ultimately did not find objective clinical evidence of post-treatment infection with *Bb* (Auwaerter & Melia, 2012; Marques, 2008; Sigal & Hassett, 2005). Essentially, the results indicate that CLD is not a “real disease.” Advocate researchers such as Fallon have fought back, critiquing clinical trials such as these for their relatively small sample sizes often consisting of patients with widely heterogeneous symptomology, which may lead to unrepresentative results (Fallon, Petkova, Keilp, & Britton, 2012). However, because the works of CLD skeptics are generally hold a high degree of constitutive credibility per their publication sources, the scientific studies and analyses of CLD advocates have been dubbed “pseudoscientific” (Auwaerter et al., 2011) or “antiscience,” a “war on evidence-based medicine” (Auwaerter & Melia, 2012). Patients’ belief in their illness have been scrutinized as indicative of undiagnosed mental health issues stemming from a lack of control (Auwaerter & Melia, 2012) and that their unexplained physical symptoms are simply psychosomatic (Hassett, Radvanski, Buyske, Savage, & Sigal, 2009). These claims by Hassett *et al*, published in the influential journal *The American Journal of Medicine* (Hassett et al., 2009), and by Auwaerter, the president of the CLD-skeptic IDSA, which creates the guidelines for diagnosis and treatment of Lyme disease,

carry significant weight in the mainstream biomedical community of physicians and scientists.

The IDSA is a highly influential professional society consisting of over 9000 infectious disease specialists that has created diagnostic and treatment guidelines for many infectious diseases including meningitis, tuberculosis, and HIV/AIDS. As a professional society with their own fellowships offered to infectious disease residents, IDSA holds great power over the future research and practice in the field of infectious disease medicine. Their well-renowned practice guidelines are the basis by which most mainstream physicians and insurance companies will base their practices surrounding infectious illnesses such as Lyme disease (“About IDSA,” n.d.). However, their Lyme disease guidelines, which oppose antibiotic retreatment in patients with long term symptomology (Wormser et al., 2006), have been the subject of their own controversy and vehement backlash from laypeople and CLD-advocate researchers and physicians (Davidsson, 2018). Notably, in response to this controversy, the CDC, longtime backers of IDSA, have removed IDSA’s Lyme guidelines from their website (Davidsson 2018), a seeming revocation of support in this area.

IDSA’s diagnostic criteria for post-treatment Lyme symptomology require a patient to have documented proof of prior Lyme disease diagnosis and antibiotic treatment (Wormser et al., 2006). Their criteria also explicitly exclude any patients whose symptomology may be explained by confounding factors such as bacterial co-infection, mental health problems, or abnormalities in their lab results such as abnormal thyroid function or a number of other serological markers which may be indicative of an undiagnosed process separate from Lyme (Lantos, 2015; Rebman et al., 2017). These wide-

sweeping exclusionary conditions may prevent a large number of CLD patients with a true illness from receiving a diagnosis and treatment.

Beyond the controversy surrounding diagnostic and treatment guidelines is the dispute over the terminology used to describe the illness as set forth by IDSA. IDSA strongly discourages the use of the term “Chronic Lyme Disease,” instead endorsing “Post-Treatment Lyme Disease Syndrome” (Maloney, 2016; Wormser et al., 2006). The term “disease” connotes a known microbiologic specificity, which due to mainstream biomedicine’s nebulous understanding of its etiology, has not been determined for CLD. IDSA opts instead to use the term “syndrome,” a word which, according to CLD advocates like Lantos, acknowledges the apparent symptoms of patients, but implies that there is no active infection, relapse, or treatment failure (Lantos, 2015). Insisting on referring to a patient’s symptomology as a syndrome rather than a disease denies discredits much of the research of CLD-advocate groups to prove the presence of persistent *Bb* infection.

A name may seem like a small detail, but as Sigal & Hassett note, a diagnosis “legitimizes the pain” (Sigal & Hassett, 2005). While a diagnosis of PTLDS does legitimize the symptomatic phenomenology experienced by long-term Lyme patients, it fails to legitimize the lived experience of many patients who do not meet the IDSA criteria for diagnosis. Ultimately, it is the apathological implications of the term “syndrome” which may lead insurance companies to deny patients antibiotic treatment (Davidsson, 2018; Maloney, 2016). The alternative diagnosis of CLD legitimizes persistent infection and opens the doors to antibiotic treatment, where a diagnosis of PTLDS may further obfuscate a patient’s understanding of their own illness and their access to care.

Because some patients may insist on a diagnosis of CLD even when mainstream doctors and insurance companies deny its existence, and therefore deny antibiotic treatment, these patients are forced to seek alternative options. Some patients who cannot find the kind of treatment they hope for or who cannot the economic strain of paying a specialist “Lyme literate medical doctor” LLMD (Davidsson, 2018) rely on complementary medical treatments such as naturopathic healers, risking their personal health outcome (Science, 2011) as well as further jeopardizing the credibility of CLD as a legitimate illness in the eyes of a mainstream biomedical paradigm that opposes alternative medicine. In order to permit CLD a greater deal of credibility and to encourage improved patients to seek care within a mainstream biomedicine, altering restrictive diagnostic and treatment guidelines is a necessity.

When CLD advocates called for a change to IDSA diagnostic and treatment criteria in 2006, a panel was arranged to reevaluate the guidelines and improve patient care. However, in a subsequent investigation by the attorney general of Connecticut, it was found that IDSA had failed to follow the National Academies of Science, Engineering, and Medicine recommendations for developing medical guidelines, which call for a diverse and balanced group of panelists (Davidsson, 2018; Johnson & Stricker, 2010). Rather, they handpicked an “artificially ‘unanimous’ panel” (Johnson & Stricker, 2010) consisting of advisors with conflicts of interest in drug companies and Lyme disease diagnostic tools, and they blocked CLD-advocates from participating in the guideline review and reform (Fred, 2008). In doing so, IDSA solidified their control over the construction of the definition and mainstream view of the illness, leading those who disagree with their guidelines to face social stigma.

SOCIAL STIGMA

We have seen how within the scientific community, researchers who speak out against IDSA guidelines or in favor of CLD's existence face social stigma and exclusion within their field when they are labeled as being "anti-science" (Auwaerter & Melia, 2012). Some advocate physicians, LLMDs, who follow alternative treatment protocols set forth by the CLD-advocate ILADS, refuse to accept insurance for fear that practicing within mainstream biomedical spheres will make them the targets of stigma and profiling as an outlier (Davidsson, 2018). LLMD and former ILADS president Daniel Cameron was reprimanded with a three-year probation for medical negligence ("Final Actions," n.d.), perhaps as a result of such profiling. This stigma trickles down to reach all interpersonal levels of the biomedical process. By defining the guidelines, the IDSA influences physicians and these physicians directly impact the experience, knowledge, and opinions of patients and pop-cultural communities. Therefore a patient who insists that they have CLD rather than PTLDS or a more well understood diagnosis may face social stigmatization not only from physicians but also from their greater social networks.

In multiple studies, CLD patients were found to feel misunderstood, isolated, not believed by their friends and family, and dismissed by their physicians (Ali, Vitulano, Lee, Weiss, & Colson, 2014; Aucott et al., 2013). "When an illness isn't medically recognized," notes CLD patient Andrew Jackson, "those around you often grow impatient or suspicious...as if your failure to recover is somehow a personal weakness" (Jackson, 2018). Pamela Weintraub, author of *Cure Unknown: Inside the Lyme Epidemic*, was told by her physicians what many CLD patients are told in their journey toward diagnosis: "It's all in your head." She shared her personal struggle with CLD at a research and advocacy panel:

“Being sick is hard enough, but being so sick for so long and also being a suspect, having your physical pain, your integrity, and your very sanity called into question as you travel the medical landscape begging for help: That is a crushing course of events.” (Science, 2011)

The feeling of self worth of CLD patients, like other sufferers of chronic pain discussed by Byron Good in his book *Medicine, Rationality, and Experience*, is often deeply affected by the constant disaffirmation they face in their fight for biomedical credibility (Good, 1994). Sigal & Hassett found that CLD patients suffer from “aporia,” or feeling hopeless, with no chance of recovery (Sigal & Hassett, 2005). This finding is in line with a 2017 study which found that 18% of patients with Lyme-associated illnesses exhibit suicidal ideation and that an each year 1,244 suicides in the USA may be a direct or indirect result of Lyme disease (Bransfield, 2017). Due to the physical and sociological hardships resulting from their illness, the overall quality of life self-reported by CLD patients has been found to be equivalent or worse to the quality of life of patients with diabetes or depression (Raphael B. Stricker & Fesler, 2018).

In direct response to the lower life functioning, aporia, and social stigma associated with CLD, patients have formed biosocialities. These CLD biosocialities primarily provide patients with social support, but through that support they aid in the development of contingent credibility for their illness within their social networks.

BUILDING BIOCITIZENSHIPS OF CLD

Rose & Novas refer to biosocial communities which seek to negotiate credibility for an illness as “citizenships” of biomedical language (Rose & Novas, 2002). The use of the term “citizenship” seems to imply that participating members are agents in a distinctly political community. This politicism is apparent in the biosociality of CLD, which has the

definitive goal of negotiating constitutive credibility for the illness around which it has formed.

Oftentimes, it is the language established by the mainstream scientific, medical, or insurance personnel around which these citizenships of biomedical language are formed (Rose & Novas, 2002). However, I argue that it is possible for a group, such as CLD's, to self-define its biosocial citizenship. A patient's prerequisite for CLD "citizenship" is an assertion of their diagnosis as genuine *chronic disease* rather than a prolonged syndrome. This assertion may be considered a political act as according to influential medical anthropologist Brown, diagnosis is often a matter of the "politics of definition," used as a tool for social control over a patient mass unfamiliar with the microbiological intricacies of their own bodies (Brown, 1995). The act of diagnosis relies heavily on a physician's handling of the precarious balance between a strict, prototypical disease definition and messy, individual experience, which is often miscommunicated and misunderstood (Good, 1994). Ultimately, this ambiguity drives the physician to be influenced by external political and social factors, which color their ultimate diagnostic decision (Aronowitz, 1991; Good, 1994).

The social and political pressures to conform to IDSA diagnostic standards or internalized biases against Lyme disease advocates may influence a doctor's decision to turn a patient away or refuse to diagnose a patient with CLD. However, the competing forces of ILADS and thousands of patients with chronic Lyme symptomology reach different conclusions from the same set of signs and symptoms, self-defining and self-constructing their idea of CLD. Through the "social construction of illness" (Brown, 1995), or the shaping of an understanding of an illness through personal phenomenological experience and

shared social experience, CLD patients construct a diagnostic politic, a community in which they thrive as “biocitizens.”

Specifically, the case of CLD constitutes an “informational biocitizenship” (Epstein 1996), which combats the use of diagnosis as a means of social control by socially constructing new definitions of CLD with biomedical knowledge. In short, informational biocitizenships fight fire with fire. Utilizing knowledge developed through scientific research and personal medical experience, informational biocitizenships encourage their members to become politically active in campaigns for recognition, credibility, and improved health outcomes for their disputed illness (Epstein 1996). Though not every member of an informational biocitizenship may hold an MD or a PhD in microbiology, when an individual’s wellbeing and livelihood is at risk, especially from a chronic illness, that individual will resist the threat of disease both immunologically and socially (Epstein 1996) by pursuing biomedical knowledge, in the end constituting them the holder of a sort of honorary degree as a “lay-expert” in their illness (Rabinow 1994). By addressing issues in science through the use of scientific terminology and knowledge, informational biocitizens can more effectively engage with members of the scientific community and develop contingent credibility for their cause. Lay-expert biocitizen activists call the current paradigm of biomedical research into question, demand expertise from the biomedical community, spread information amongst laypeople, and combat stigma, all while supporting the ill (Epstein 1996, Brown 1997).

BIOSOCIAL ACTIVISM

To date, there is little information in the scientific or sociological academic communities as to how activism within CLD informational biosocial citizenships has directly influenced research and re-definition of the illness, however there is sufficient evidence, to suggest that these interactions exist and are ongoing. As discussed in the introduction, CLD biocitizen activism may be evaluated on three levels: the individual biocitizen's effect on the biosociality, activism within the biosociality, and the biosociality's effects on biomedical institutions.

BIOCITIZEN → BIOSOCIALITY

The CLD biocitizen may best contribute to radical conversations to reevaluate and re-define their illness by sharing narrative accounts of their illness experience with the wider public. Narrative illness accounts are a form of activism in and of themselves, giving space to voices and stories often silenced by mainstream biomedicine. Because the delocalized pain experienced in chronic illnesses like CLD resists the ability to pinpoint illness experience to a certain part of the physical body, constructing a narrative of the illness experience allows the biocitizen to localize their pain in history and story, enabling them to envision a future in which they may overcome the adversity caused by their illness (Good 1994). Although, as Good notes, using patient narratives in healing may be unorthodox or unscientific by the standard biomedical paradigm, qualitative research has shown that personal narrative constructions of chronic illness can improve patient wellbeing and aid physicians in developing a more nuanced analysis and empathetic understanding of their patient's illness (Good 1994).

When CLD patients develop and share their narrative illness experiences, they perform activism by redefining the meaning of their illness on a personal level and aiding their own healing process. When these narratives are shared with their greater biosocial community, biocitizens perform activism through community healing. Hearing patients with similar experiences lets individual CLD patients, dismissed by biomedical and social communities, know that they are not alone.

In her book *Cure Unknown*, Pamela Weintraub, a CLD patient herself, shares the stories of her family's battle to gain recognition for their CLD as well as the stories of patients whom she interviewed over the course of 8 years. In her autobiographical report, Weintraub shares her own experiences with Lyme symptoms and the pain of not being believed, garnering empathy from her biosocial audience. For her "fatigue was the worst symptom," and she criticizes studies which "minimize these 'subjective' symptoms as almost irrelevant." By criticizing biomedical studies through the lens of personal illness experience, she calls her biosociality to action to question the studies relevant to their care. She later decries CLD-skeptic researchers who in her view may wrongly believe that "the answer sought by science [by CLD patients] should be endless antibiotic treatment," instead explaining that to truly "help these patients, medicine must acknowledge [patient] pain, and science must deal with the complexity [of the illness]" (Science, 2011). Through the use of narrative, Weintraub is able to build rally support from her community and direct that support in a biosocial activist direction for improved research outcomes.

Other narrative accounts include Aaron Jackson's in which he delves further into the psychological and biological implications of CLD, directly engaging with and challenging the biomedical understanding of his diagnosis, which took him three years to find. He

describes his suicide attempt, recovery, and his journey to “understand [himself]—and give meaning to the world and to [his] relationships—in new ways,” further sharing that writing narratives about his CLD experience has been healing and has “helped with his ongoing process of self-remaking.” In the months since his article was self-published, Jackson has received a number of comments from other members of the CLD biosociality thanking him for sharing his insights, which have been a source of support (Jackson, 2018). Other celebrity biocitizens of CLD like Avril Lavigne, Amy Tan, Yolanda Hadid, and Darryl Hall have all been outspoken advocates for their illness’s credibility, sharing their narratives with the public (LymeDisease.org).

BIOSOCIALITY → BIOSOCIALITY

Biocitizens may engage with these narratives, and with their biosociality as a whole, through online informational resources. The Internet has become an invaluable source of narrative illness information to learn how to manage ill bodies, a “digital commons” (Rose & Novas, 2002) of biomedical information that aids in the development of informational biocitizenships (Harrington, 2008). Patients with Chronic Fatigue, Fibromyalgia, and other chronic illnesses have used the health narratives of their community as a resource for cataloguing symptomology and discovering effective management options (Rose & Novas 2002). CLD narratives published online such as Jackson’s (Jackson, 2018) add to a growing body of readily accessible knowledge which may aid other patients in dealing with their illness.

Many of these narratives may be found on blogs and forums such as *Tired of Lyme* or *r/Lyme* on reddit.com. The first of these forums was *lymenet.org*, created by university

student Marc Gabriel in an effort to distribute free information regarding Lyme disease to the population that needed it most (Mervine, 2014). The medium of the online forum allows direct engagement within the CLD biosociality, allowing for further development of biosocial activism.

In certain blog posts of *Tired of Lyme*, the author asserts his membership in the CLD biosociality by utilizing the pronoun “we” when discussing the CLD experience, signaling his allyship as a fellow politically active biocitizen. In reference to advising patients on seeking an official diagnosis, he asks “how do we simplify as best as we can, something that has really grown unnecessarily complex?” The forums act as radical alternative medicine centers of self-help in which CLD patients walk one another through the steps of navigating the mainstream biomedical sphere to get a diagnosis and treatment. As an important note, the members and contributors to these sites are not medical experts and much of their advice, while well-meaning, may ultimately be harmful to the biosocialities they are trying to help. For example, the *Tired of Lyme* blog suggests that patients who are convinced they have undiagnosed CLD circumnavigate the biomedical bureaucracy of diagnosis and self-diagnosing by provoking an immune response through dietary supplements (“I Think I Have Lyme Disease But My Doctor And Lab Tests Say I Don’t,” n.d.).

However, rather than seeking treatment advice, many CLD patients simply search the forums for support, posting threads with titles such as “In search of encouragement, sharing experiences w/ treatment,” “Here’s my problem...GETTING PEOPLE TO HEAR ME!!!” and “Going public with a CLD diagnosis; Thanks for speaking out” (“Lyme Disease (and related tick-borne infections) • r/Lyme,” n.d.; “Lyme Disease Support & Consolation,” n.d.). Before online forums were available, patients utilized newsletters to communicate and share

stories (Mervine, 2014). The supportive relationships between CLD patients developed through biosocial forums evolve into grassroots activist movements, pushing for real world change in illness credibility, recognition, and re-definition.

BIOSOCIALITY → MAINSTREAM BIOMEDICINE

It is at this stage that CLD activism progresses from intra-biosocial activism to establish its own institutional presence within the biomedical and political sphere. Large, established advocacy networks such as the International Lyme and Associated Diseases Society (ILADS) and LymeDisease.org represent invaluable informational hubs where CLD patient-biocitizens, medical professionals, and researchers may connect. These organizations seem to act as a form of institutional biosocialities.

Started as a grassroots advocacy movement in 1989 by CLD patient Phylis Mervine, LymeDisease.org, at that point known as the California Lyme Disease Association (CALDA), was one of the first major advocacy organizations to grow out of biocitizen activism. They aim to provide free health care and legal policy analysis for patients who may have trouble securing insurance coverage beyond the acute phase of Lyme disease (“About LymeDisease.org,” n.d.). In 1993, members of LymeDisease.org set a precedent for political activism surrounding CLD when they protested a lack of patient recognition and representation at a senate hearing. Later, in 2000, a group of biocitizen activists pushed congressmen to investigate Lyme disease researchers at the CDC, for fear that researchers’ conflicts of interest in pharmaceutical companies or diagnostic technology may skew their results. Although no conflicts of interest were found in the CDC investigation (Auwaerter et

al., 2011), CLD biocitizens had proved themselves as a vocal activist force to be reckoned with, one with an ever-growing presence.

This growing support influenced physicians and researchers to join the movement, resulting in the founding of ILADS in 1999. Through funding their own biomedical research by Lyme advocates, ILADS seeks to combat biases or conflicts of interest from the other side of the “Lyme Wars.” Through the years they have also have developed their own primer course in Lyme disease treatment for physician advocates and maintain a database of LLMDs for patients struggling to find a sympathetic healthcare provider (“About,” n.d.)

An ally of LymeDisease.org, the Lyme Disease Association created a petition to have the IDSA diagnostic and treatment guidelines removed from the National Guideline Clearinghouse (NGC) database. While not outright stated by the Lyme Disease Association, it is reasonable to assume that they are in favor of the more inclusive guidelines set forth by ILADS. Garnering over 45,000 signatures, this petition helped lead to an investigation of the IDSA guidelines by the NGC in 2016, which found the guidelines to be outdated. The NGC, an initiative of the US Department of Health and Human Services, provides evidence-based practice guidelines and informational materials to healthcare professionals (“Official Word on IDSA Guidelines’ Removal from NGC,” n.d.). Their removal of the IDSA guidelines signifies the potential of political power held by large-scale biocitizen activism.

The political traction built by the CLD biosociality has lead to the formation of the Interagency Lyme and Tick-Borne Disease Working Group of the U.S. Department of Health & Human Services (HHS), established by Congress in 2016 as part of the 21st Century Cures Act. The goal of the working group is to review scientific literature and epidemiological and medical efforts regarding tick-borne diseases, including Lyme disease. A total of 11 patients,

including a number of CLD biocitizens, serve on the working group alongside government employees, scientists, and physicians (Davidsson, 2018; Mervine, 2018a). Several CLD biosociality advocates from LymeDisease.org volunteer on subcommittees within the working group. Jill Auerbach, one of the patients selected to serve on the working group by the HHS, noted the significance of her participation, and the participation of her biosocial peers on the panel, expressing that “prior to this, the Lyme community was left in the dark without being considered” (Mervine, 2018b).

As an institutional biosociality, LymeDisease.org holds such a degree of sway in the political evaluation of CLD that when biocitizens became concerned that a particular member of the working group may have a financial conflict of interest, LymeDisease.org’s petition to have him replaced received more than 10,000 signatures in less than four days, leading to the swift replacement of the working group member in question and preserving the advocacy interests of the greater CLD informational biocitizenship (Mervine 2018a). Patient participation in the Lyme and Tick-Borne Disease Working Group has certainly allowed new voices to be heard in the discussion of preset guidelines and scientific studies already performed, allowing for a retrospective alteration in the understanding of Lyme disease. However, the act of *creating* the scientific knowledge for the working group to review is another story.

DEMOCRATIZING SCIENTIFIC KNOWLEDGE-CREATION

DECONSTRUCTING A SCIENTIFIC “HEGEMONY”

In their ethnography *Laboratory Life*, Latour & Woolgar, influential anthropologists in the field of Science & Technology Studies, refer to science as “hegemonic,” inaccessible

to those without advanced degrees or social connections to aid them in receiving sought-after grants. They describe this hegemony as hidden and misunderstood by the general public, resulting in the popular view becoming a tautology: scientists are perceived by the public to operate scientifically simply because of the fact that they are scientists (Latour & Woolgar, 1979). While I believe that much of the general public perceives science and scientists in a more nuanced manner, understanding the intellectual value cultivated by years of education and work in the field, there is evidence that the tautological view exists. For example, a study which uses “scientific” language and is published in a well-known journal may be perceived to be scientific (and therefore perceived to be true) because it was produced by scientists. The danger of this tautology is that the scientific knowledge produced from within this so-called hegemony does not only garner the constitutive credibility inherent to its nature as collected data, but contingent credibility in the collective consciousness of the lay population, stemming from the power of the “scientific scientist.” The general public therefore may refrain from questioning researchers, assuming that due to their status of power scientists always create the most credible knowledge.

The idea of hegemonic science appears the most rigid in the hard scientific fields of physics or chemistry, which rarely affect the public’s day-to-day life. However, when it comes to the biomedical sciences, the hegemony breaks down. To ensure the best health outcomes for patients, microbiologists and immunologists cannot sequester themselves in laboratories; they must collaborate with psychologists, sociologists, and patients themselves. Pharmaceutical researchers are forced to postulate difficult moral dilemmas: is it better to maintain purity of the scientific process or to address the bioethical violation of giving subjects placebos, knowing they will not work (Epstein 1996). In the case of human health

researchers, ill patients are the very subjects of the research and are therefore both directly affected by and inherently involved in the research process.

According to Epstein, the most effective way to advance medical science, especially in complex illnesses such as HIV/AIDS or CLD, is to test new treatments on willing bodies, necessarily centralizing laypeople in the biomedical research and knowledge-making process (Epstein 1996). Yet, beyond objectified bodies, the role of laypeople in the construction of knowledge, which most directly affects them, their very wellbeing, is still limited.

For an illness such as CLD which is expanding in scope each year and yet remains deeply misunderstood and controversial on both a biological and social level, this limitation is concerning. Though there are over 300,000 new national cases every year, according to ClinicalTrials.gov, there are fewer annual studies on Lyme disease than on Leprosy, which only has an annual incidence of 200 (Johnson, Shapiro, et al., 2018). There is no lack of need for information or patient requests for information, so I find it surprising how little Lyme disease research is actually being performed. Between 1994 and 2004, less than 1% of all topics researched in biomedicine were proposed by the lay-population (Oliver, Armes, & Gyte, 2009). While perhaps representative of the “hegemonic” nature of science, this would not generally be perceived as an alarming statistic so long as researchers make successful strides in improving health outcomes. However, for an illness as socially and biologically complex as CLD, it is my opinion that the voices and questions of the biocitizen patients, those with the deepest understanding of the illness, need to be heard. By taking informational biocitizens’ questions into account, the body of Lyme research will increase in size, but also perhaps in quality.

The democratization of epidemiology through directly involving biosocialities in the scientific processes that affect them is not a new idea. A trend for patient-participatory health research began in the 1990s, especially in regards to community-level studies to discern ecological and pollutant causes for illnesses. Since that time, multiple participatory programs have been widely supported by the National Institute of Environmental Health Science, the National Cancer Institute (NCI), the Department of Defense, and the CDC (McCormick, Brody, Brown, & Polk, 2004).

BARRIERS & IMPACT OF PATIENT PARTICIPATION

Though models for participatory research exist and are encouraged by national organizations, the voices of CLD biocitizens are still often ignored by mainstream science. For biocitizens to perform biosocial activism by participating directly in the research process, three primary barriers must be overcome: prejudices held by researchers and participants, problems of recruitment, and a lack of scientific knowledge among the lay population (Oliver et al., 2009).

Science that has been successfully incorporated CLD biocitizens has surmounted these barriers by drawing from models for participatory research as set forth by Oliver, de Wit, and Alba & Broerse. Through active recruitment and education of biocitizens by scientists within their biosocial communities (de Wit, Bloemkolk, Teunisser, & van Rensen, 2015), patients may gain a “cultural competence” in science (Epstein, 1996) which allows them to participate intelligently and on equal footing with their academic colleagues. Successful participatory studies may include biocitizens filling any role in the “Ladder of Participation” as developed by Arnstein (1969) from research subject to informer, advisor, or

project initiator (Abma & Broerse, 2010). It should be noted that in the model of biocitizen participation in scientific research, while maximized lay-participation and a balanced viewpoint is desired, this participation does not undermine the work of scientists that is so critical to biomedical advancement (Mervine, 2018b). Rather it is the collaboration between biocitizens and allied researchers that is the true benefit and strength of participatory research.

The democratic construction of scientific knowledge can lead to greater empathy within the scientific community toward the patient population and a reduction in patients' distrust toward the scientific process which has, from their perspective, often wronged or ignored them (McCormick 2004; Oliver 2009). When patient participants utilized narratives of their illness experiences in the question formulation process for possible research topics, panel members in the scientific community reported an alteration in their perspective, leading to greater sensitivity toward patient needs and emotions (Oliver 2009). Monica White, president of the Colorado Tick-Borne Disease Awareness Association and member of the Lyme and Tick-Borne Disease Working Group has said in reference to the importance of lay-participation in the scientific process, ““You don't “get it” [understand] the same way until you “get it” [contract the illness]”” (Mervine 2018b). Biocitizen participation in CLD research has the potential to change the views of influential biomedical researchers, drawing allies from across the trenches of the Lyme Wars.

Through a newfound understanding and empathy between both parties, the proposed research questions may shift focus. Typically scientists are focused on more technical issues while the general public is more concerned with personal ethical or social risks (McCormick 2004), but as biocitizens engage with researchers, the scientific hegemony must become

flexible and begin to listen to the demands of the ill (Harrington 2008). It is this collaboration and flexibility which will be necessary in future CLD research endeavors to improve diagnostic abilities and treatment options for patients.

DEMOCRATIC RESEARCH IN CLD

Though limited in scope, there do exist tangible examples of previous successful lay-participation in CLD research. Within the Lyme and Tick-Borne Disease Working Group, biocitizen participants have worked to eliminate the barrier of difficult scientific jargon by promoting accessible, Lyme-friendly language in scientific and governmental papers. As well-informed lay-experts, the patient panel members are able to “hold their own” with representatives from the FDA and NIH (Mervine 2018b). Biocitizens’ engagement in scientific discourse with members of the scientific community has been successful in establishing mutual trust between the parties as well as establishing further credibility for CLD. In the acknowledgements of one paper by Sigal & Hassett, active members of the CLD-skeptic research camp (Fig. 1), they thank CLD patients for “having taught us so well that it is really not ‘all in my head’” (2002).

The most successful example of democratization of CLD research to date is the MyLyme Data project started by LymeDisease.org. MyLyme Data is a crowd-sourced database of patient information including symptomology and past and current treatment courses which may be utilized by researchers with funding from the National Science Foundation (“About LymeDisease.org,” n.d.). To date, nearly 11,000 patients with both acute and CLD are enrolled in the registry, consisting of a much broader experience range than that of most Lyme disease studies (Johnson et al., 2018). Typical Lyme disease research

recruits only those patients who meet the CLD-skeptic IDSA diagnostic criteria. For the purposes of minimizing confounding variables in data and maximizing generalizability to other Lyme disease research, this choice makes perfect sense. However, because the IDSA criteria exclude a large number of the patients that advocacy networks like LymeDisease.org attempt to understand with their research, the use of broad-scale recruitment of heterogeneous patients from the CLD biosociality is logical. As a caveat, it should be noted that while a broadly applicable and heterogeneous population could theoretically exist for a passively recruited database like MyLyme Data, in reality the registered patients, recruited via social media, are over 80% female and predominantly older and highly educated (Johnson et al., 2018). Though the patient-base is skewed, the large patient-base heterogeneity of symptomology alone warrants attention and credibility for the data collected by the registry.

Illustrating the potential power that democratized science may hold for CLD patient health are two studies by Johnson utilizing the MyLyme. In the first, Johnson surveyed a total of 7000 participants from the registry consisting of physicians, scientists, and CLD biocitizens to determine their top research priorities. The research priorities of the biocitizens were all questions directly impacting patient day-to-day wellbeing, with specific focuses on harm reduction, health restoration, and improved life functioning. These included new therapy options, improved diagnostic tests, and the development of rehabilitation protocol (Johnson, et al., 2018).

A second study by Johnson took some of these biocitizen priorities into account, performing what is perhaps the largest CLD scientific study to date. In examining the self-reported symptomology of a subset of 4000 CLD patients from the MyLyme Data registry, it

was determined that the three most prominent CLD symptoms were fatigue, aches and pains, and neurological issues including insomnia, memory loss, headaches, and neuropathy (Johnson, Shapiro, et al., 2018). The results of this “patient-powered” study have implications for further research and redefinition of CLD. The illness’s current nebulous definition, or lack thereof, is in part what causes so much of the controversy in the biomedical field. By cataloguing CLD symptoms at a large scale, this study may help in pinpointing a symptomological definition for CLD, giving it a degree of constitutive credibility.

Outside of “patient-powered” studies, the primary way in which biocitizens may participate in research is through patient-funded studies. Multiple medical anthropologists have noted that part of the so-termed hegemonic power of science is that scientists or their affiliated organizations run the labs doing the research (Epstein, 1996; Latour & Woolgar, 1979). Epstein has stated that in order to truly democratize the process of biomedical knowledge-creation, informational biocitizenships must construct their own laboratories (Epstein, 1996). According to de Wit, it is often the case in rare diseases that patients initiate the research process (de Wit et al., 2015). I believe that patient initiation of the research process through the construction of allied laboratories is also necessary to democratize knowledge-creation in the case of misunderstood illnesses like CLD. Started as grassroots fundraising efforts, large advocacy networks like LymeDisease.org now fund this democratized research, supporting numerous allied researchers (Fig. 4) (“About LymeDisease.org,” n.d.).

LymeDisease.org also supports other biocitizen-interest ventures such as the publication of a quarterly journal, *Lyme Times*, which allows them to contribute to the

democratic development and access of biomedical knowledge by publishing the research and opinions of CLD advocates who are often targeted as “antiscience” (Auwaerter et al., 2011) by more mainstream periodicals. Fallon, a regular contributor to *Lyme Times*, has performed a great deal of research regarding CLD in an effort to determine the illness’s biomechanism and reappraise antibiotic treatment protocols (Fallon et al., 2009, 2012). Another long time contributor, Stricker, has published numerous articles regarding the need to redefine CLD and to reevaluate IDSA guidelines regarding PTLDS/CLD and has performed research in an effort to prove persistent *Bb* bacterial infection in CLD patients (Johnson & Stricker, 2010; Middelveen, Fesler, & Stricker, 2018; Middelveen, Sapi, et al., 2018; R. B. Stricker & Winger, 2001; Raphael B. Stricker & Fesler, 2018). The funding for patient-centered CLD research provided by biosocial advocacy networks like LymeDisease.org, ILADS, or the Lyme Disease Association, often from the direct donations of biocitizens and allies, has led to numerous advancements in the scientific understanding of CLD. Do to the ongoing controversy these scientific advancements may not receive the amount of constitutive credibility they deserve in the eyes of mainstream biomedicine. However, as biocitizens continue to contribute to the biomedical knowledge-creation process and push for further developments, allied researchers are on the verge of reaching new frontiers in CLD redefinition and treatment.

NEW FRONTIERS IN CLD RESEARCH & REDEFINITION

Much of the research funded by CLD-allied institutions aims to establish new methodologies for more accurate diagnostic tests as well as finding proof of persistent *Bb* infection. Recently, researchers backed by Lyme disease organizations and the mainstream

NIH, have developed new methods and criteria for Lyme disease diagnosis up to 20% more reliable than traditional testing methods (Lahey et al., 2015; Shah et al., 2007). Other patient-centric studies have established statistically significant differences in symptomology between CLD patients and healthy patients who previously had Lyme disease (Chandra et al., 2010; Chandra, Wormser, Marques, Latov, & Alaedini, 2011). By providing evidence of a consistent symptomological experience of CLD, these studies have implications for improving the view of CLD as a distinct diagnosis. Understanding the biomechanism of CLD in an effort to increase its biomedical credibility has also been a priority of recent research ventures (Aucott et al., 2016; Jacek et al., 2013; Soloski et al., 2014; Touradji et al., 2018)

Perhaps the most impactful biocitizen-inspired research for negotiating the credibility of CLD, allowing patients to overcome the controversy and stigma surround their illness, is to prove that CLD is truly what it claims to be: a chronic infectious disease. The general etiological theory is that *Bb* act as persister or “sleeper cell” bacteria similar to *E. coli* or *Salmonella*. These persisters are dormant “invisible” phenotypes of the bacteria that can resist antibiotics, which act most effectively on actively growing and dividing cells (Berndtson, 2013; Middelveen, Sapi, et al., 2018). Compelling evidence from infected animal models and humans has shown that *Bb* can survive antibiotic treatment (Aucott et al., 2016; Embers et al., 2017; Middelveen, Sapi, et al., 2018). Notably, the cited study by Middelveen *et al.* discusses its results as individual case studies, exemplifying the democratic, patient-participatory nature of the research and demonstrating respect for the CLD biosociality by maintaining individual patient narrative experience in the creation of scientific knowledge.

With evidence of persistent *Bb* infection, and therefore constitutive credibility for CLD, biocitizen activists may push back against the strict IDSA guidelines of PTLDS diagnostics to redefine the illness, giving it credibility as a true *disease*. Allied researchers have proposed a new working definition and diagnostic criteria for CLD (Raphael B. Stricker & Fesler, 2018). Stricker & Fesler's new guidelines democratize the diagnostic process, allowing biocitizens to play an active role in their diagnosis by forcing clinicians to work in conjunction with their patients, relying heavily on their clinical judgment and the narrativized illness experiences of their patients as diagnostic tools.

The use of patient experience as research method has been utilized successfully in CLD scientific research as well. By using qualitative interviews (Ali et al., 2014) or questionnaires (Rebman et al., 2017) as well as examining the socioeconomic implications of illness (Davidsson, 2018), scientists have taken a more holistic, biopsychosocial look at CLD to better understand its social and biological symptomology and to better treat said symptomology.

Some scientists have focused on alternative treatment options for patients who have become disillusioned with traditional biomedicine or who desire supplements to a typical antibiotic course. Goc & Rath found promising results for *Uncaria tomentosa* (Cat's Claw) and *Otoba parvifolia* (Otoba bark) which both demonstrated significant anti-*Bb* properties, as well as a variety of other natural ingredients such as grape seed, wild cherry, sage, and oregano (Goc & Rath, 2016). Tinctures made of these natural ingredients have been cited as treatment supplements by the biosocial activist blog *Tired of Lyme* ("Samento and Lyme Disease Treatment," n.d.). Although the lay-biocitizen blog may be home to some questionable medical advice, this is one positive instance in which popularized knowledge

and self-treatment experience of the CLD informational biocitizenship can feed back into the biomedical research and treatment development process. The cycle of CLD's developed credibility through biosocial action (Fig. 1) may perhaps be better understood when examined through its historical predecessors.

HISTORICAL CONTEXT

The phenomenon of biocitizen activism greatly influencing biomedical research and redefinition of illness has been seen again and again throughout recent history, most notably with the examples of HIV/AIDS, breast cancer, and psychological disorders such as PTSD. Psychological disorders and HIV/AIDS are highly stigmatized illnesses to this day, just like CLD. However, in the second half of the 20th century, even breast cancer patients who spoke out against mainstream biomedicine were called “hysterical” (Epstein, 1996).

Just as CLD patients do today, in response to this social stigma, patients with HIV/AIDS, breast cancer, and psychiatric disorders developed informational biocitizenships around their expertise based on their own lived experience and used this expertise to challenge scientific experts (Epstein, 1996; McCormick et al., 2004). Similar to the list of patient research requests developed through the MyLyme Data project (Johnson, et al., 2018), these biocitizen predecessors demanded research in line with the needs of the patient base (Harrington, 2008; McCormick et al. 2004). Even when considered as “non-experts” or the “political fringe” by the mainstream biomedical cannon, these activist communities have been successful in creating meaningful debate within biomedicine (Coleman, 2008).

In the case of psychiatric patients, the debate created by a grassroots organized conference to challenge the social definition and mainstream understanding of mental illness

may have lead to a better biological understanding of mental illness experience (Coleman, 2008). The debate over HIV/AIDS treatment advancements and research ethics (Epstein 1996) led to drug companies speeding up the research and approval process for antiretroviral drugs, greatly reducing patient mortality by the late 1990s (Harrington 2008). These reconsiderations of research bioethics and understandings of disputed illness have influenced the debates and activism lead by CLD biocitizens today.

The biosocialities of HIV/AIDS and breast cancer also laid the groundwork for democratized scientific research and negotiations of credibility for stigmatized illness. When HIV/AIDS biocitizens made it clear that the scientific community must meet their demands, the Cancer Research Institute (CRI) invited participants into the research process where they helped make decisions as to what should be studied and what methods would be the most ethical and user-friendly. When the demands of breast cancer patients were ignored by mainstream biomedicine, biocitizens performed “organized non-compliance” by establishing their own alternative health clinics and research societies (Epstein 1996). When it was recognized that these new lay-experts had valuable experiences and thoughts to participate to the scientific process, breast cancer biocitizens became heavily involved in research surrounding the environmental causes of the illness. Even today, “Patient-Powered Research” foundations like Dr. Susan Love’s Army of Women, are heavily emphasized in the breast cancer biosociality (Johnson, 2014), similar to the ally organizations founded by CLD biocitizens.

In the process of negotiating credibility for a definition of CLD as a true disease, biocitizens may look for inspiration in the Post-Traumatic Stress Disorder (PTSD) biosociality. After the Vietnam War, veterans displaying symptoms PTSD were often

dismissed or ignored by mental health professionals. Activist veterans worked together with sympathetic psychiatrists to push for the creation of the official diagnostic classification of PTSD in 1980, successfully redefining an experienced illness and allowing them to get definitive help (Arksey 1994). From this example, the CLD biocitizen may glean that in order to gain credibility for their illness and improve their chances for improved health, both biomedical activism and collaboration with allies in mainstream biomedicine are necessary.

CONCLUSION

The struggle to legitimize CLD and redefine its biomedical understanding is not the first time Lyme disease has had to be reevaluated. The illness was once defined merely by arthritic symptoms as “Lyme Disease Arthritis” (Aronowitz, 1991). Biomedicine is a messy art. Patients, physicians, and researchers each hold their own piece of the puzzle that makes up the complete picture of illness experience. From these individual pieces, each party develops their own understanding of the completed image, but I believe that only by allowing patient biocitizens to partake in the knowledge-creation approach to put *all* the pieces together may true understanding be developed.

Thanks to the collaborative work of active biocitizens and allied researchers, great strides have been made in the development of scientific knowledge, and therefore constitutive credibility for CLD. However, the “Lyme Wars” and controversy rage on. Through continued biosocial activism, more contingent credibility for the illness must be established amongst the general public and in the minds of researchers to dismantle biases held against CLD. Further democratized, patient-centered research will be critical to redefining CLD in a way that is satisfactory to the sufferers of the illness and the greater

biomedical community, especially the IDSI. Particularly, more research must be conducted on treatment options for patients with CLD, including further studies on antibiotic use and alternative treatment options. Additionally, more interdisciplinary analysis on the cycle (Fig. 1) of CLD biocitizen advocacy and biomedical research must be conducted to see how “popularized knowledge feeds back into the research process” (Epstein 1996) to better understand the gaps in connectivity between the fields that lead to poor mental and physical health outcomes.

REFERENCES

- Abma, T. A., & Broerse, J. E. W. (2010). Patient participation as dialogue: setting research agendas: Patient participation as dialogue. *Health Expectations*, *13*(2), 160–173. <https://doi.org/10.1111/j.1369-7625.2009.00549.x>
- About. (n.d.). Retrieved December 6, 2018, from <https://www.ilads.org/about/>
- About IDSA. (n.d.). Retrieved December 6, 2018, from <https://www.idsociety.org/about-idsa/about-idsa/>
- About LymeDisease.org. (n.d.). Retrieved December 6, 2018, from <https://www.lymedisease.org/about-us/who-we-are/about-lymedisease-org/>
- Ali, A., Vitulano, L., Lee, R., Weiss, T. R., & Colson, E. R. (2014). Experiences of patients identifying with chronic Lyme disease in the healthcare system: a qualitative study. *BMC Family Practice*, *15*, 79. <https://doi.org/10.1186/1471-2296-15-79>
- Aronowitz, R. (1991). Lyme Disease: The Social Construction of New Disease and Its Social Consequences. *The Milbank Quarterly*, *69*(1), 79–112.
- Aucott, J. N., Rebman, A. W., Crowder, L. A., & Kortte, K. B. (2013). Post-treatment Lyme disease syndrome symptomatology and the impact on life functioning: is there something here? *Quality of Life Research*, *22*(1), 75–84. <https://doi.org/10.1007/s11136-012-0126-6>
- Aucott, J. N., Soloski, M. J., Rebman, A. W., Crowder, L. A., Lahey, L. J., Wagner, C. A., ... Bechtold, K. T. (2016). CCL19 as a Chemokine Risk Factor for Posttreatment Lyme Disease Syndrome: a Prospective Clinical Cohort Study. *Clinical and Vaccine Immunology : CVI*, *23*(9), 757–766. <https://doi.org/10.1128/CVI.00071-16>

- Auwaerter, P. G., Bakken, J. S., Dattwyler, R. J., Dumler, J. S., Halperin, J. J., McSweegan, E., ... Wormser, G. P. (2011). Antiscience and ethical concerns associated with advocacy of Lyme disease. *The Lancet. Infectious Diseases*, *11*(9), 713–719. [https://doi.org/10.1016/S1473-3099\(11\)70034-2](https://doi.org/10.1016/S1473-3099(11)70034-2)
- Auwaerter, P. G., & Melia, M. T. (2012). Bullying Borrelia: When the Culture of Science is Under Attack. *Transactions of the American Clinical and Climatological Association*, *123*, 79–90.
- Berndtson, K. (2013). Review of evidence for immune evasion and persistent infection in Lyme disease. *International Journal of General Medicine*, *6*, 291–306. <https://doi.org/10.2147/IJGM.S44114>
- Bransfield, R. C. (2017). Suicide and Lyme and associated diseases. *Neuropsychiatric Disease and Treatment*, *13*, 1575–1587. <https://doi.org/10.2147/NDT.S136137>
- Brown, P. (1995). Naming and Framing: The Social Construction of Diagnosis and Illness. *Journal of Health and Social Behavior*, *34*–52. <https://doi.org/10.2307/2626956>
- Cameron, D. J., Johnson, L. B., & Maloney, E. L. (2014). Evidence assessments and guideline recommendations in Lyme disease: the clinical management of known tick bites, erythema migrans rashes and persistent disease. *Expert Review of Anti-Infective Therapy*, *12*(9), 1103–1135. <https://doi.org/10.1586/14787210.2014.940900>
- Chandra, A., Wormser, G. P., Klempner, M. S., Trevino, R. P., Crow, M. K., Latov, N., & Alaedini, A. (2010). Anti-neural antibody reactivity in patients with a history of Lyme borreliosis and persistent symptoms. *Brain, Behavior, and Immunity*, *24*(6), 1018–1024. <https://doi.org/10.1016/j.bbi.2010.03.002>

- Chandra, A., Wormser, G. P., Marques, A. R., Latov, N., & Alaedini, A. (2011). Anti-Borrelia burgdorferi Antibody Profile in Post-Lyme Disease Syndrome. *Clinical and Vaccine Immunology : CVI*, 18(5), 767–771. <https://doi.org/10.1128/CVI.00002-11>
- Coleman, E. G. (2008). The Politics of Rationality: Psychiatric Survivor's Challenge to Psychiatr. In *Tactical Biopolitics : Art, Activism, and Technoscience* (pp. 341–364). Cambridge, MA: MIT. Retrieved from <http://web.a.ebscohost.com.ccl.idm.oclc.org/ehost/ebookviewer/ebook?sid=81c75a9e-1e79-4719-8b66-e8414b6d6780%40sessionmgr4007&vid=0&format=EB>
- Controversies and Challenges. (n.d.). Retrieved October 7, 2018, from <https://www.ilads.org/research-literature/controversies-challenges/>
- Davidsson, M. (2018). The Financial Implications of a Well-Hidden and Ignored Chronic Lyme Disease Pandemic. *Healthcare (Basel, Switzerland)*, 6(1). <https://doi.org/10.3390/healthcare6010016>
- de Wit, M., Bloemkolk, D., Teunissen, T., & van Rensen, A. (2015). Recommendations for Successful Patient Involvement in Scientific Research. *Tijdschrift Voor Gezondheidswetenschappen*, (3).
- Embers, M. E., Hasenkampf, N. R., Jacobs, M. B., Tardo, A. C., Doyle-Meyers, L. A., Philipp, M. T., & Hodzic, E. (2017). Variable manifestations, diverse seroreactivity and post-treatment persistence in non-human primates exposed to Borrelia burgdorferi by tick feeding. *PLoS ONE*, 12(12). <https://doi.org/10.1371/journal.pone.0189071>

- Epstein, S. (1996). *Impure Science: Aids, Activism, and the Politics of Knowledge* (1st ed.). University of California. Retrieved from <https://www.ucpress.edu/book/9780520214453/impure-science>
- Fallon, B. A., Lipkin, R. B., Corbera, K. M., Yu, S., Nobler, M. S., Keilp, J. G., ... Sackeim, H. A. (2009). Regional cerebral blood flow and metabolic rate in persistent Lyme encephalopathy. *Archives of General Psychiatry*, *66*(5), 554–563. <https://doi.org/10.1001/archgenpsychiatry.2009.29>
- Fallon, B. A., Petkova, E., Keilp, J. G., & Britton, C. B. (2012). A Reappraisal of the U.S. Clinical Trials of Post-Treatment Lyme Disease Syndrome. *The Open Neurology Journal*, *6*, 79–87. <https://doi.org/10.2174/1874205X01206010079>
- Feng, J., Shi, W., Zhang, S., & Zhang, Y. (2015). Persister mechanisms in *Borrelia burgdorferi*: implications for improved intervention. *Emerging Microbes & Infections*, *4*(8), e51. <https://doi.org/10.1038/emi.2015.51>
- Final Actions. (n.d.). Retrieved December 6, 2018, from <https://apps.health.ny.gov/pubdoh/professionals/doctors/conduct/factions/PhysicianDetailsAction.action?finalActionId=8470>
- Fred, H. L. (2008). “Chronic” Dishonesty in Medicine? *Texas Heart Institute Journal*, *35*(2), 226.
- Goc, A., & Rath, M. (2016). The anti-borreliae efficacy of phytochemicals and micronutrients: an update. *Therapeutic Advances in Infectious Disease*, *3*(3–4), 75–82. <https://doi.org/10.1177/2049936116655502>
- Good, B. (1994). *Medicine, Rationality, and Experience*. Cambridge University.

- Harrington, M. (2008). AIDS Activists and People with AIDS: A Movement to Revolutionize Research and for Universal Access to Treatment. In *Tactical Biopolitics: Art, Activism, and Technoscience* (pp. 323–340). Cambridge, MA: MIT.
- Retrieved from <http://web.a.ebscohost.com/ccl.idm.oclc.org/ehost/ebookviewer/ebook?sid=81c75a9e-1e79-4719-8b66-e8414b6d6780%40sessionmgr4007&vid=0&format=EB>
- Hassett, A. L., Radvanski, D. C., Buyske, S., Savage, S. V., & Sigal, L. H. (2009). Psychiatric Comorbidity and Other Psychological Factors in Patients with “Chronic Lyme Disease.” *The American Journal of Medicine*, 122(9), 843–850.
- <https://doi.org/10.1016/j.amjmed.2009.02.022>
- Hsu, V. M., Patella, S. J., & Sigal, L. H. (1993). “Chronic lyme disease” as the incorrect diagnosis in patients with fibromyalgia. *Arthritis & Rheumatism*, 36(11), 1493–1500.
- <https://doi.org/10.1002/art.1780361103>
- I Think I Have Lyme Disease But My Doctor And Lab Tests Say I Don’t. (n.d.). Retrieved December 6, 2018, from <http://www.tiredoflyme.com/i-think-i-have-lyme-disease-but-my-doctor-and-lab-tests-say-i-dont.html>
- ILADS Treatment Guidelines. (n.d.). Retrieved December 5, 2018, from <https://www.ilads.org/patient-care/ilads-treatment-guidelines/>
- Jacek, E., Fallon, B. A., Chandra, A., Crow, M. K., Wormser, G. P., & Alaedini, A. (2013). Increased IFN α Activity and Differential Antibody Response in Patients with a History of Lyme Disease and Persistent Cognitive Deficits. *Journal of Neuroimmunology*, 255(1–2), 85–91. <https://doi.org/10.1016/j.jneuroim.2012.10.011>
- Johnson, L. (2014). Patient-Powered Research. *Lyme Times*, 26(3), 36.

- Johnson, L., JD, & MBA. (2018, August 9). MyLymeData: A Patient-Centered Presentation on Having Lyme Disease. Retrieved November 11, 2018, from <https://www.lymedisease.org/members/lyme-times/special-issues/tick-borne-disease/mylymedata/>
- Johnson, L., Shapiro, M., Mankoff, J., Johnson, L., Shapiro, M., & Mankoff, J. (2018). Removing the Mask of Average Treatment Effects in Chronic Lyme Disease Research Using Big Data and Subgroup Analysis. *Healthcare*, 6(4), 124. <https://doi.org/10.3390/healthcare6040124>
- Johnson, L., & Stricker, R. B. (2010). The Infectious Diseases Society of America Lyme guidelines: a cautionary tale about the development of clinical practice guidelines. *Philosophy, Ethics, and Humanities in Medicine : PEHM*, 5, 9. <https://doi.org/10.1186/1747-5341-5-9>
- Klempner, M. S., Baker, P. J., Shapiro, E. D., Marques, A., Dattwyler, R. J., Halperin, J. J., & Wormser, G. P. (2013). Treatment Trials for Post-Lyme Disease Symptoms Revisited. *The American Journal of Medicine*, 126(8), 665–669. <https://doi.org/10.1016/j.amjmed.2013.02.014>
- Lahey, L. J., Panas, M. W., Mao, R., Delanoy, M., Flanagan, J. J., Binder, S. R., ... Robinson, W. H. (2015). Development of a Multiantigen Panel for Improved Detection of *Borrelia burgdorferi* Infection in Early Lyme Disease. *Journal of Clinical Microbiology*, 53(12), 3834–3841. <https://doi.org/10.1128/JCM.02111-15>
- Lantos, P. M. (2015). Chronic Lyme Disease. *Infectious Disease Clinics of North America*, 29(2), 325–340. <https://doi.org/10.1016/j.idc.2015.02.006>

- Latour, B., & Woolgar, S. (1979). *Laboratory Life: The Construction of Scientific Facts*. Princeton, NJ: Princeton University Press. Retrieved from <http://www.jstor.org/stable/j.ctt32bbxc.6>
- Lyme Disease (and related tick-borne infections) • r/Lyme. (n.d.). Retrieved December 6, 2018, from <https://www.reddit.com/r/Lyme/>
- Lyme Disease Support & Consolation. (n.d.). Retrieved December 6, 2018, from <http://www.tiredoflyme.com/>
- Maloney, E. L. (2016). Controversies in Persistent (Chronic) Lyme Disease. *Journal of Infusion Nursing, 39*(6), 369–375. <https://doi.org/10.1097/NAN.000000000000195>
- Marques, A. (2008). Chronic Lyme Disease: A Review. *Infectious Disease Clinics of North America, 22*(2), 341–360. <https://doi.org/10.1016/j.idc.2007.12.011>
- McCormick, S., Brody, J., Brown, P., & Polk, R. (2004). Public Involvement in Breast Cancer Research: An Analysis and Model for Future Research. *International Journal of Health Services, 34*(4), 625–646. <https://doi.org/10.2190/HPXB-9RK8-ETVM-RVEA>
- Mervine, P. (2014). The First Decade: The Unabashed History of a Grassroots Advocacy Effort Tells a Tale of Vision and Fortitude. *Lyme Times, 26*(1), 6–10.
- Mervine, P. (2018a, August 9). How the Patient Voice Has Impacted the Tick-Borne Disease Working Group. Retrieved November 11, 2018, from <https://www.lymedisease.org/members/lyme-times/special-issues/tick-borne-disease/patient-voice/>
- Mervine, P. (2018b, August 9). Lyme Patients Involved with Tick-Borne Disease Working Group Offer Their Opinions. Retrieved November 11, 2018, from

- <https://www.lymedisease.org/members/lyme-times/special-issues/tick-borne-disease/patients-offer-opinions/>
- Middelveen, M. J., Fesler, M. C., & Stricker, R. B. (2018). History of Morgellons disease: from delusion to definition. *Clinical, Cosmetic and Investigational Dermatology*, *11*, 71–90. <https://doi.org/10.2147/CCID.S152343>
- Middelveen, M. J., Sapi, E., Burke, J., Filush, K. R., Franco, A., Fesler, M. C., & Stricker, R. B. (2018). Persistent *Borrelia* Infection in Patients with Ongoing Symptoms of Lyme Disease. *Healthcare (Basel, Switzerland)*, *6*(2). <https://doi.org/10.3390/healthcare6020033>
- Official Word on IDSA Guidelines' Removal from NGC. (n.d.). Retrieved December 6, 2018, from <https://www.lymediseaseassociation.org/index.php/lda-news-a-updates/1456-official-word-on-idsa-guidelines-removal-from-ngc>
- Oliver, S., Armes, D., & Gyte, G. (2009). Public Involvement in Setting a National Research Agenda. *The Patient*, *2*, 179–190. <https://doi.org/10.2165/11314860-000000000-00000>
- Rebman, A. W., Bechtold, K. T., Yang, T., Mihm, E. A., Soloski, M. J., Novak, C. B., & Aucott, J. N. (2017). The Clinical, Symptom, and Quality-of-Life Characterization of a Well-Defined Group of Patients with Posttreatment Lyme Disease Syndrome. *Frontiers in Medicine*, *4*. <https://doi.org/10.3389/fmed.2017.00224>
- Rebman, A. W., Crowder, L. A., Kirkpatrick, A., & Aucott, J. N. (2015). Characteristics of seroconversion and implications for diagnosis of post-treatment Lyme disease syndrome: acute and convalescent serology among a prospective cohort of early

- Lyme disease patients. *Clinical Rheumatology*, 34(3), 585–589.
<https://doi.org/10.1007/s10067-014-2706-z>
- Rose, N., & Novas, C. (2002). Biological Citizens. *Global Anthropology*, 45.
- Samento and Lyme Disease Treatment. (n.d.). Retrieved December 7, 2018, from
<http://www.tiredoflyme.com/samento.html>
- Science, I. of M. (US) C. on L. D. and O. T.-B. D. T. S. of the. (2011). *The Social Construction and Human Face of Tick-Borne Disease*. National Academies Press (US). Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK57014/>
- Shah, J. S., Cruz, I. D., Wronska, D., Harris, S., & Harris, N. S. (2007, April). Comparison of specificity and sensitivity of IGeneX Lyme Western Blots using IGeneX criteria and CDC criteria for a positive Western Blot. *Townsend Letter: The Examiner of Alternative Medicine*, (285), 129-.
- Sigal, L. H., & Hassett, A. L. (2002). Contributions of societal and geographical environments to “chronic Lyme disease”: the psychopathogenesis and aporology of a new “medically unexplained symptoms” syndrome. *Environmental Health Perspectives*, 110(Suppl 4), 607–611.
- Sigal, L. H., & Hassett, A. L. (2005). Commentary: ‘What’s in a name? That which we call a rose by any other name would smell as sweet.’ Shakespeare W. Romeo and Juliet, II, ii(47–48). *International Journal of Epidemiology*, 34(6), 1345–1347.
<https://doi.org/10.1093/ije/dyi180>
- Soloski, M. J., Crowder, L. A., Lahey, L. J., Wagner, C. A., Robinson, W. H., & Aucott, J. N. (2014). Serum Inflammatory Mediators as Markers of Human Lyme Disease Activity. *PLoS ONE*, 9(4). <https://doi.org/10.1371/journal.pone.0093243>

- Stricker, R. B., & Winger, E. E. (2001). Decreased CD57 lymphocyte subset in patients with chronic Lyme disease. *Immunology Letters*, 76(1), 43–48.
- Stricker, Raphael B. (2007). Counterpoint: long-term antibiotic therapy improves persistent symptoms associated with lyme disease. *Clinical Infectious Diseases: An Official Publication of the Infectious Diseases Society of America*, 45(2), 149–157.
<https://doi.org/10.1086/518853>
- Stricker, Raphael B., & Fesler, M. C. (2018). Chronic Lyme Disease: A Working Case Definition. *American Journal of Infectious Diseases*, 14(1), 1–44.
<https://doi.org/10.3844/ajidsp.2018.1.44>
- Tonks, A. (2007). Lyme wars. *BMJ: British Medical Journal*, 335(7626), 910–912.
<https://doi.org/10.1136/bmj.39363.530961.AD>
- Touradji, P., Aucott, J. N., Yang, T., Rebman, A. W., & Bechtold, K. T. (2018). Cognitive Decline in Post-treatment Lyme Disease Syndrome. *Archives of Clinical Neuropsychology: The Official Journal of the National Academy of Neuropsychologists*. <https://doi.org/10.1093/arclin/acy051>
- Jackson, A. (2018, June 13). When Doctors Don't Listen. Retrieved October 1, 2018, from <https://www.sapiens.org/body/chronic-lyme-disease-treatment/>
- Wormser, G. P., Dattwyler, R. J., Shapiro, E. D., Halperin, J. J., Steere, A. C., Klemperer, M. S., ... Nadelman, R. B. (2006). The Clinical Assessment, Treatment, and Prevention of Lyme Disease, Human Granulocytic Anaplasmosis, and Babesiosis: Clinical Practice Guidelines by the Infectious Diseases Society of America. *Clinical Infectious Diseases*, 43(9), 1089–1134. <https://doi.org/10.1086/508667>