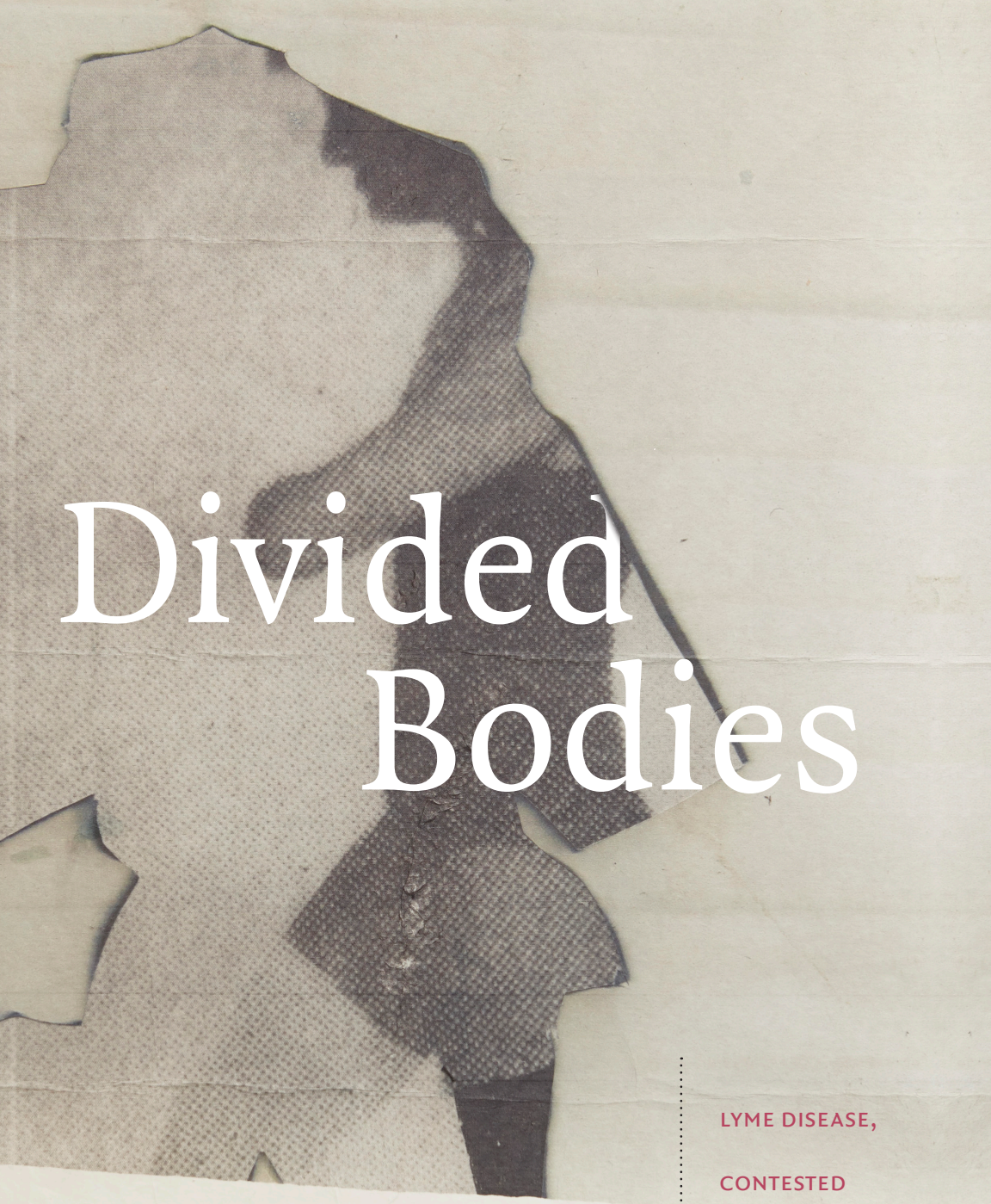

Divided Bodies

LYME DISEASE, CONTESTED ILLNESS, AND EVIDENCE-BASED MEDICINE

ABIGAIL A. DUMES

Divided Bodies

CRITICAL
GLOBAL
HEALTH:
EVIDENCE,
EFFICACY,
ETHNOGRAPHY

A series edited by
Vincanne Adams
and João Biehl

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Abigail A. Dumes

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FOR JOHN, ABE, AND ROSE,
MY HEART AND HOME

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Introduction

LYME DISEASE OUTSIDE IN

On October 5, 2013, Lyme disease advocates organized a protest against the Infectious Diseases Society of America (IDSA). The protest took place in San Francisco, in front of the convention center where the IDSA was holding its annual conference. Protesters wore lime green clothing and displayed signs that read, "IDSA: Revise Lyme Guidelines," "IDSA Ticks Me Off," and "Chronic Lyme Affects Me Every Day. Revise Your Guidelines." The protest also featured speeches by patients and advocates and an original song by a Lyme patient rapper. In the weeks leading up to the protest, a Lyme advocacy group circulated a petition urging the National Guidelines Clearinghouse (NGC), an organization that, at the time, housed all US clinical practice guidelines, to remove the IDSA's Lyme disease guidelines from its website. Although the IDSA maintained that its guidelines for diagnosing and treating Lyme disease were based on the "best available evidence," Lyme disease advocates argued that the guidelines were "outdated," did not recognize the biological basis of chronic Lyme disease, and denied access to the care that patients need.

Over the past four decades, patient advocacy events like the IDSA protest, increased media attention, and growing numbers of reported Lyme disease cases have brought the controversy over how to diagnose and treat Lyme disease into the national spotlight. Indeed, Lyme disease is one of the most controversial medical issues in the United States, and, like other illnesses whose biological reality is contested, including chronic fatigue syndrome, Gulf War syndrome, and multiple chemical sensitivity, it is replete with class action lawsuits, patient protests, polarizing documentaries, congressional hearings, and state and federal investigations. The crux of Lyme's controversy is whether the disease can persist beyond standard

antibiotic treatment. While proponents of the "mainstream" standard of care claim that Lyme disease is easily diagnosed and treated, proponents of the "Lyme-literate" standard of care claim that diagnostic tests are unreliable and that Lyme disease can persist in the form of "chronic Lyme disease," a condition that mainstream proponents do not recognize but which Lyme-literate proponents argue should be treated with extended courses of antibiotics.[1] The response to this medical impasse has been twofold: individuals on both sides of the divide have taken legal and political action to try to regulate how Lyme patients are diagnosed and treated; many have also turned to environmental measures (e.g., deer hunting, pesticides, and landscaping) to protect those at risk and to prevent the further spread of Lyme disease.

This book sits at the heart of the disagreement over how to diagnose and treat Lyme disease, and it explores why, in an era of evidence-based medicine, the systematic production and standardization of evidence has *amplified* rather than *diminished* disagreement related to contested illnesses. Institutionalized in the United States in the late 1980s and early 1990s, evidence-based medicine is an approach to standardizing clinical care that promotes the use of clinical guidelines and the hierarchization of scientific evidence, at the top of which is the "objective" evidence of randomized controlled trials and at the bottom of which is the "subjective" evidence of expert opinion. As the introductory vignette reveals, Lyme disease draws attention to the emerging centrality of evidence-based medicine—particularly clinical guidelines—to the experiences and practices of American biomedicine. As the basis for treatment, insurance, and public health decisions, clinical guidelines are an increasingly salient dimension of patients' and physicians' everyday lives. Because Lyme's controversy hinges on differences over how to clinically manage Lyme disease and, more critically, whether chronic Lyme disease has an objective evidentiary basis, clinical guidelines are urgently relevant to Lyme patients and physicians. For all patients with contested illnesses, which evidence gets to count toward the substantiation and formal recognition of their suffering is paramount.

Over the course of my research for this book, as I spent time with Lyme patients at support group meetings or observed physicians who treat Lyme disease at their offices, I was often asked whether my research would "solve" the controversy. In response to this question, I was quick to manage expectations because, for many, this question ultimately meant, "Will your research determine whether chronic Lyme disease exists?," which is beyond the purview of an anthropological engagement. But for others, this question

meant, "Why has the controversy lasted so long? And what is preventing its resolution?" At the time, I assumed this question was also tangential to my project, since anthropologists are often better equipped to answer questions that begin with *how* instead of *why*. In the end, however, the countless stories and observations I collected suggested otherwise. Drawing from eighteen months of research among Lyme patients, physicians, and scientists in the United States, this book attempts to answer *why* the rise of evidence-based medicine has made contested illnesses like Lyme disease even *more contested* despite the fact that the aim of evidence-based medicine is to resolve medical dispute.

To the anticipated disappointment of some, my answer to this question has less to do with a *cover-up* and more to do with an *uncovering*. As the stories of Lyme patients, physicians, and scientists show, the emergence of evidence-based medicine has contributed to the perceived delegitimation of contested illnesses through the formal categorization of "medically unexplainable illness." This term has often been used interchangeably in biomedical practice with somatoform disorder and is understood by many biomedical physicians to be "the repeated medical help-seeking for multiple medical symptoms without organic disease" and, in many cases, "the expression of psychological illness through physical symptoms" (Burton 2003, 231; see also Hatcher and Arroll 2008; Nimnuan, Hotopf, and Wessely 2001). Although the history of physical ailments perceived to lack a biological basis is long (S. Johnson 2008, 13), it was only with the rise of evidence-based medicine that these ailments became formally recognized as medically unexplainable and, as a result, were excluded from the trappings of medical legibility, including an insurance code, eligibility to be the object of clinical studies, and corresponding pharmaceutical treatments and clinical guidelines. Through formal categorization, patients with contested illnesses (chronic Lyme patients foremost among them) have become bound together in a more cohesive and more visible "biosociality" of "delegitimized" suffering that has allowed them to mobilize against their medical marginalization, mobilizations no more clearly demonstrated than in the Lyme patient community's protest against the IDSA.[2]

At the same time that evidence-based medicine has hardened the boundary between explainable and unexplainable illnesses, it has also unexpectedly offered patients a path to perceived biological legitimacy by providing a platform on which individuals inside and outside the medical arena can make claims to medical truth. In the case of Lyme disease, these truth claims are made in two ways. The first are the embodied and symptomatic

expressions of unwellness that Lyme patient advocates and Lyme-literate physicians (as their patients' proxies) make heard through digital and social media, legislative lobbying, the design of clinical trials, and the writing of clinical guidelines. The second are scientific claims based on interpretations of a range of published evidence. As "citizen experts," Lyme patients' claims to the biological reality of their ill health are simultaneously grounded in embodied experience *and* scientific knowledge—a phenomenon nicely captured in the bannered backdrop to the Lyme patient community's 2014 protest against the IDSA in Philadelphia, which read, "IDSA Stop Rejecting Science! Lyme Patients are Suffering!" (Orsini 2008, 111).[3] Intended to streamline medical opinion, evidence-based medicine has instead produced a proliferation of opinions and, more critically, has created the opportunity for patients as well as practitioners to draw on the authority of evidence-based medicine to validate their experiences and make their opinions heard. In its exploration of Lyme's fractured reality, this book not only offers the first ethnographic analysis of the Lyme disease controversy but also brings into focus the social complexities of contested illness within the increasingly standardized bounds of US biomedicine.

Contextualizing Lyme

With more than three hundred thousand estimated new cases each year, Lyme disease is the most commonly reported vector-borne infectious disease in the United States.[4] Discovered in 1982, *Borrelia burgdorferi*, the bacterium that causes Lyme disease, is transmitted by the bite of *Ixodes scapularis*, the blacklegged tick, in the eastern United States and *Ixodes pacificus* in the western United States.[5] Although Lyme disease affects women and men of all ages, it disproportionately affects those who live in areas that deer, small rodents, and ticks prefer to inhabit: the suburbs or areas on the periphery of forested land (Stafford 2007). More critically, because of the geopolitics of suburban development, Lyme disease is understood to primarily affect those above and well above the national poverty level. For example, only 3 percent of Connecticut residents who are below the poverty line live in towns in the "highest quintile of Lyme disease rates" (Cromley and Cromley 2009, 10). For this reason and others, Lyme disease has become known by some as a "yuppie disease."[6] Like other illnesses perceived to be medically unexplainable, chronic Lyme disease is also perceived to be more common among women. In contrast to the perceived environmental and social specificity of its risk, Lyme disease's biophysical manifestations are under-

stood by many to be characterized by marked generality. Aside from a diagnostic "bull's-eye" rash known as erythema migrans (EM), many across the standard-of-care divide argue that both early and late Lyme disease are characterized by nonspecific symptoms (i.e., symptoms associated with a spectrum of other disorders) and, because of their clinical ambiguity, are often misdiagnosed.

Differences in biomedical practice and opinion are the rule not the exception.[7] It *is* exceptional, however, that a disagreement over the diagnosis and treatment of one disease would be so pronounced that it would manifest in the institutionalization of two biomedical standards of care.[8] Proponents of the mainstream standard of care diagnose early Lyme by an EM rash or a positive antibody test, treat with two to four weeks of antibiotics, and in doing so, adhere to the clinical guidelines formulated by the IDSA and adopted by the Centers for Disease Control and Prevention (CDC). Mainstream proponents argue that the bacterium that causes Lyme disease, *Borrelia burgdorferi*, does not persist in the body at pathogenic levels after standard antibiotic therapy. As a result, these physicians perceive chronic Lyme disease (the attribution of symptoms that persist beyond antibiotic treatment to persistent *Borrelia* infection) to be one of a range of medically unexplained illnesses. That is, they classify chronic Lyme as an "illness" (a subjective experience of physical distress) rather than a "disease" (a condition substantiated by biophysical markers that warrants biophysical intervention). In this way, the mainstream standard of care can be more fully understood as a "dominant epidemiological paradigm," one that is "produced by a diverse set of social actors who draw on existing stocks of institutional knowledge to identify and define a disease and determine its etiology, proper treatment, and acceptable health outcomes" (P. Brown, Morello-Frosch, and Zavestoski 2012, 84). As a "belief system and a practice" that is "historically contingent," a dominant epidemiological paradigm becomes entrenched and endures, but it is also changeable, even if that change occurs over protracted periods of time (2012, 105).

On the other side of the debate, proponents of the Lyme-literate standard of care diagnose Lyme based on a complex manifestation of symptoms with or without a positive antibody test, treat patients with extended oral and intravenous antibiotics, and in doing so, adhere to the clinical guidelines published by the International Lyme and Associated Diseases Society (ILADS), the professional organization created in opposition to the IDSA in 1999.[9] Unlike the mainstream camp, the Lyme-literate camp is supported by a patient base of "activated health citizens" who are organized around

their shared delegitimized suffering (G. Davis and Nichter 2015).[10] In this way, chronic Lyme patients take part in what sociologist Phil Brown and colleagues have described as "embodied health movements" and "boundary movements," movements that are centered around the "embodied experience of illness" and that actively challenge medical and scientific doxa (P. Brown, Morello-Frosch, and Zavestoski 2012, 16, 27–29).[11] That is, patients engage in "boundary work," attempting to reconfigure the boundaries between "science" and "nonscience" (2012, 27–28; see Gieryn 1983) while also engaging *with* "boundary objects," such as evidence-based medicine, that move across boundaries between scientists and "lay experts" and can be differentially deployed depending on whose hands they are in (Star and Greisemer 1989; Epstein 1995, 1996; see also Cordner 2016).[12]

Despite critical differences in how the mainstream and Lyme-literate communities interpret Lyme disease, both seek to establish credibility through the scientific authority of evidence-based medicine. To date, scientists have conducted five randomized controlled trials on the therapeutic effects of extended antibiotics for Lyme disease patients. Although intended to resolve dispute, randomized controlled trials have, in this case, provided a means by which each camp, through different "styles of scientific practice," has reinforced its respective standard of care (Fujimura and Chou 1994, 1017). Grounded in interdisciplinary explorations of medical epistemologies, biopower, and environmental health, this book intervenes to explore how the controversy over how to diagnose and treat Lyme disease sheds light on the tangled relationship between contested illness and evidence-based medicine in the United States.

The Divided Bodies of Contested Illness

To make sense of the Lyme disease controversy, I have described Lyme disease as a contested illness. But what do I mean by contested illness? This term is most often used by sociologists, and most notably by Phil Brown and those affiliated with the former Contested Illness Research Group at Brown University, to mean "diseases or conditions in which there is dispute over environmental causation."[13] For these sociologists, approaches to understanding contested illness are "situated at the intersection of environmental health and environmental justice."[14] More recently, anthropologist Joseph Dumit has described "emerging, contested illnesses," such as chronic fatigue syndrome, Gulf War syndrome, and multiple chemical sensitivity, as "illnesses you have to fight to get" (2006) or "new sociomedi-

cal disorders" (2000) and has suggested that they are characterized by five features: chronicity, biomentality, therapeutic diversity, cross-linkage, and legal explosivity (2006, 578).[15]

My use of contested illness is a departure from previous applications because in more broadly describing contested illness as any bodily condition whose biological basis is disputed, it insists that these illnesses are not limited to environmental causation and highlights the inextricability of their relationship with evidence-based medicine. This approach to contested illness has less to do with causation, the effects of contestation, and defining features than with the conditions of possibility that produce "medically unexplainable illness" as a diagnostic category.[16] For example, because evidence-based medicine has formalized the importance of objective over subjective evidence in the diagnosis of disease, illnesses that present with more symptoms (subjective markers of disease) than they do signs (objective markers of disease) bring out epistemic differences *within* biomedical practice over the extent to which symptoms can be used to substantiate and explain the biological reality of illness. And because of these epistemic differences, patients with contested illnesses straddle the divide between the experience of living a disease and the experience of being perceived to have a medically unexplainable illness.

The analysis in this book, then, draws on the concept of "divided bodies" to highlight the epistemic and embodied tensions that characterize the phenomenon of contested illnesses in an era of evidence-based medicine; that is, contested illnesses are disorders over which bodies of *thought* are divided, and they are also bodily conditions that are always *experienced* as diseases but are often *perceived* to be illnesses. As a result, those who live, diagnose, and treat contested illness often make corollary and competing claims to, on the one hand, biological legitimacy and, on the other, "epistemo-legitimacy" (the legitimacy of how contested illness should be known) (Fassin 2018a). For example, in the case of Lyme disease, and within an evidence-based framework that privileges the legitimacy of objective over subjective evidence, claims to biological legitimacy hinge on the biological reality of bacterial persistence in patients' bodies, while competing claims to epistemo-legitimacy hinge on divergent approaches to the relationship between symptoms and signs in how Lyme disease should be known.

Over the course of this book, I also suggest that evidence-based medicine's role in amplifying disagreement over the biological reality of contested illnesses is the product of a foundational feature of bio-

medicine: the relative importance of the *sign* versus the *symptom* in the diagnosis and treatment of ill health. While evidence-based medicine attempts to achieve a more scientific medicine by eliminating bias and, in particular, clinical reliance on the subjectivity of symptoms, the rub is that no matter how many randomized controlled trials are performed and no matter how sophisticated technology becomes, patients continue to experience ill health through their symptoms. As a result, symptomatic experience continues to remain the bedrock of clinical care. This is no truer than for contested illnesses, in which patients and practitioners must often navigate a range of perplexing symptoms in the absence of definitive signs.

And yet, just because patients experience their ill health symptomatically as an *illness* does not mean that they do not also experience their ill health as a *disease*, if by disease we mean an organic pathological process that affects organs and systems of the body. As anthropologist Stefan Ecks observes, the "illness/disease opposition" has been a hallmark feature of medical anthropology since the late 1970s, "when medical anthropologists insisted on recovering subjective 'illness' experiences from below medicine's overpowering definitions of objective 'disease'" (2008, S83). First outlined by psychiatrist Leon Eisenberg in 1977 and soon after elaborated on by medical anthropologist Arthur Kleinman, illness has been understood within anthropology as the "innately human experience of symptoms and suffering," while disease has been understood as "what the practitioner creates in the recasting of illness in terms of theories of disorder," that is, "an alteration in biological structure or functioning" (1988, 3–6). Although the distinction between illness and disease—and a subsequent shift in scholarly focus to the sociocultural dimensions of health and medicine—has been one of medical anthropology's most significant contributions, its equally significant flaw is that it reproduces and reifies biomedicine's binaries of experience/knowledge, subjectivity/objectivity, and patient/practitioner and, in doing so, does not take into account the possibility that patients actually *live*—or in Annemarie Mol's words "do"—disease (Mol 2002).[17] In the case of Lyme disease, *living* disease means that in addition to the symptomatic feeling of unwellness, Lyme patients also feel, imagine, internalize, enact, and act on ideas of the Lyme bacterium living inside them, morphing into different states, hiding in their tissues and other parts of their bodies, proliferating and dying, and interacting with their immune system, all of which are ideas drawn from a scientific understanding of Lyme disease as a biological entity. It is precisely this divided experience of living a disease while

being perceived to have an illness within the context of divided bodies of thought that uniquely characterizes the phenomenon of contemporary contested illness.

While proponents of evidence-based medicine have assumed that a more scientific medicine would help to create an amoral and apolitical foundation for clinical care, in practice, as this book underscores, evidence-based medicine has reinforced biomedicine's moral and political dimensions. Indeed, within the now immanent institutional framework of evidence-based medicine, the distinction between medically explainable and medically unexplainable conditions can be more fully understood as a normative delineation between the "right" and "wrong" ways of being sick.[18] In the everyday lives of Lyme patients and other patients with contested illness, being sick in the wrong way means that they are at risk for being perceived by physicians and other patients as good or bad individuals who make good or bad choices about their health, a reality that, of course, has consequences for the delivery and distribution of their medical care. Much has been written about medicalization and biomedicalization and the process by which features of everyday life become the objects of biomedical attention and intervention; less has been written about bodily conditions that are actively excluded from biomedicine's embrace and the epistemic processes by which they are categorized as *unexplainable* and, as a result, *unmedicalizable*.[19] Approaching biomedicine as a "stratified process" that is "simultaneously expansionist and exclusionary," this book explores biomedicine's exclusionary features by attending to one condition perceived to be unexplainable—chronic Lyme disease—and the implications of its unexplainability (Klawiter 2008, 28).

The Biopower and Biolegitimacy of Evidence-Based Medicine

If evidence-based medicine has succeeded in adjudicating the right and wrong ways to be sick in the United States according to a rubric of medical explainability that privileges certain types of evidence over others, it is because it is a potent site of power. But what is the nature of this power? And what is the source of its potency? In this book, I suggest that evidence-based medicine can be more fully understood as both a technology of biopower *and* a form of "biolegitimacy," an argument that builds on Didier Fassin's critical interpretation of Michel Foucault's work on biopower.[20] Against the grain of much biopolitical scholarship, Fassin suggests that Foucauldian biopower—or power "situated and exercised at the level of life"—actually

has little to do with "life as such" and is much more about how, through "biopolitics" (the regulation of populations) and "anatomo-politics" (the "set of disciplines practiced on the body"), populations and individuals are governed (Rabinow and Rose 2006, 196; Fassin 2011, 185). In this way, Fassin argues that biopower can be more accurately described as "power over life," and that an attendant and perhaps more salient feature of the contemporary world is biolegitimacy: a "legitimacy of life" that "affirms" "the value of life as supreme good" but is always in tension with a "politics of life" that simultaneously produces an "inequality of the worth of lives in the real world" (2018b, 66, 116).[21] As a technology whose object is the improvement of individual and collective health *and* a means through which bodies are legitimated at the same time that they are hierarchized, assigned "unequal worth," and "differentially treated," evidence-based medicine invites analytical attention to how biopower *and* biolegitimacy operate in everyday life (92).

For example, as a "form of truth discourse" and a "strategy for intervention upon collective existence in the name of life and health," evidence-based medicine is animated by the biopolitical idea that "making live" can be made more "effective and efficient" through the taxonomic organization of medical evidence (Rabinow and Rose 2006, 203–4; Foucault [1997] 2003, 247).[22] And because, as Foucault observes, "power is everywhere," the source of evidence-based medicine's power is not uniquely held by the state but flows through and is operationalized simultaneously by state, nonstate, and individual entities (Foucault [1976] 1990, 93).[23] Indeed, state institutions (e.g., departments of health, the CDC, the Food and Drug Administration, and the National Institutes of Health), nonstate institutions (e.g., medical boards and professional societies), *and* individual bodies police the boundaries between "normal" and "pathological," "risk" and "benefit," "good practice" and "bad practice," and "science" and "quackery." To do this, as Lyme disease and other contested illnesses reveal, these regulatory bodies have increasingly come to rely on medicine's "'soft' biomedical technology" of legibility and standardization: evidence-based medicine (and, in particular, the randomized controlled trial) (Lowy 2000, 49).[24] More critically, evidence-based medicine is intensely biopolitical because, in its uptake by patients as well as physicians and scientists, it is also produced and sustained through individual and everyday "practices of the self, in the name of individual or collective life or health" (Rabinow and Rose 2006, 204).[25]

As I explore in this book, however, evidence-based medicine is much more than a set of biopolitical practices, technologies, and institutions that

regulate clinical care—it is also a form of biolegitimacy that produces epistemic truths about the biological body and legitimizes differences between the right (or medically explainable) and wrong (or medically unexplainable) ways to be sick. The case of Lyme disease suggests that evidence-based medicine's power over life can be more fully attributed to its democratic and ecumenical appeal and the attendant perception of its innocuous—if not benevolent—nature. That evidence is widely understood and promoted to be "a good thing" and that clinical guidelines are widely understood and promoted to be "voluntary" are key to evidence-based medicine's strength, for these features widen evidence-based medicine's reach and allow it to be used as a lingua franca that makes biological life "sacred" through coordinated efforts to improve it *and* reinforces the "differential evaluation of concrete lives" (Fassin 2018b, 126).[26] The ethnographic study of the relationship between evidence-based medicine and contested illness also highlights how, in the context of biomedicine, claims to biological legitimacy are inextricably linked to epistemo-legitimacy, since claims to the biological legitimacy of contested illnesses are validated and strengthened by knowledge about the body that is recognized as legitimate *at the same time* that knowledge about the body is validated and strengthened by the biological legitimacy of patients' embodied experiences. Here, I make a distinction between biolegitimacy and biological legitimacy. Where biolegitimacy is a pervasive "legitimacy of life," biological legitimacy is a desired state of biomedical inclusion to which individuals make claims—for themselves and on behalf of others—within a framework of biolegitimacy (66).

In its attention to "life as biology" and "life as biography," this book explores the experience and practice of evidence-based medicine as both a technology of biopower and a form of biolegitimacy, and it sheds light on the *lived* political implications of the institutionalization of medical standards in the United States (Fassin 2011, 190). In doing so, this book reveals the extent to which standardization has become a critical component of the management of individual and collective health and a means by which certain conditions of the body come to matter more than others.

Researching Lyme

Between 2010 and 2011, I spent eighteen months traveling by car, train, ferry, and plane throughout the northeastern, mid-Atlantic, and western United States to spend time with and observe Lyme patients, physicians,

and scientists. The research methods I used were a familiar anthropological combination of participant observation, unstructured and semistructured interviews, and popular, academic, and social media analysis. As a participant observer, I shadowed physicians on either side of the standard-of-care divide, and I regularly attended critical sites of discourse and practice in the Lyme disease controversy, including patient support group meetings, scientific laboratory and public health meetings, fundraising events, and scientific conferences. In addition to conducting hundreds of informal interviews at these sites, I also conducted 145 semistructured interviews with patients, physicians, and scientists, in addition to health officials, politicians, and patient advocates.[27] Finally, because a significant portion of Lyme disease discourse takes place online, I tracked the publication and circulation of relevant articles, blog posts, and listserv emails. Together, the data derived from the range of methods I used allowed me to piece together analytical insights into the lived experience of Lyme's controversy.

My first points of contact were with support group leaders and patient advocates. Within a matter of months, I was attending and observing the weekly and monthly meetings of five patient support groups, all of which were located within the same state in the northeastern United States. Although they differed in size and the regularity of their meetings, all the support group meetings I attended followed a similar format. Members would begin by introducing themselves to others and would then describe their experiences with Lyme disease; many would provide updates about remedies they had tried since the last meeting or about changes in their health status. The task of describing their experiences often brought members to tears, the reason why many group leaders kept a box of tissues on hand. Relevant issues that surfaced when members shared their stories often led to lively discussions that would eventually be reined in by the group leader so that the next member could share their story.

All five of the support groups I observed had a core group of members that attended every meeting; other members attended when they could, and each meeting was often attended by one or two new members. Members' experiences with Lyme disease were wide ranging: many had been undergoing treatment for years, while others had just been diagnosed with Lyme disease and were hoping to learn more information, having heard from friends and family that Lyme disease could be a persistent problem. Some members were unaware of the Lyme disease controversy, while others were acutely aware, having participated in advocacy events and read a range of advocacy-related materials. Attending patient support group meetings al-

lowed me to understand patients' experiences as fully as possible; it also introduced me to a larger network of patients. It was with these patients that I began to conduct in-home interviews. I also recruited patient interviewees through email listservs and at Lyme disease fundraisers and patient advocacy events. These interviews, of which I conducted thirty-four, were audio recorded and often lasted two to three hours, as patients' stories often stretched back decades and included the stories of multiple family members.

As I gained traction with Lyme patients, I also reached out to physicians and scientists. Their response was equally positive, even if, like patients and advocates, they were also cautious. After explaining the nature and aims of my project—and particularly if I had been introduced by a colleague whom they trusted—mainstream and Lyme-literate physicians invited me to observe their practices, and scientists agreed to let me observe their activities. Only a handful of physicians and scientists did not respond to my email inquiries. In total, I observed seven physicians' practices on either side of the standard-of-care divide, as well as the meetings and activities of four scientific laboratories. In addition to asking me about my project, mainstream physicians and scientists were particularly interested in learning about what it was like to spend time with chronic Lyme patients and Lyme-literate physicians. I told them what I told Lyme patients and Lyme-literate physicians: that we talked a lot about Lyme disease and that each side wondered how I could spend so much time in the company of the other side.

To make sense of the antipodal perceptions that characterize the Lyme controversy, I began, during my fieldwork, to assume an ethnographic stance inspired by quantum mechanics that I call "quantum ethnography."[28] A physics term, quantum mechanics hinges on the discomfiting idea that one thing can be in two or more places at once. Unlike the familiar model of multisited ethnography, quantum ethnography is not a spatial practice but a conceptual one. That is, when conducting research, no matter where I was or with whom I was speaking, I tried always to occupy multiple perspectives within the parameters of my project's field and, in doing so, attempted to map out relations between these perspectives and between myself and these relations. Unlike methodological relativism, which requires the suspension of one's own perspective to understand another perspective, quantum ethnography required that I *fully and simultaneously inhabit* every perspective of which I was aware. In this way, quantum ethnography draws from "a feminist epistemology that insists that all claims to truth must be located," but it also attempts to push this work further by creating an ethnographic

roadmap to capture and represent a range of situated perspectives *across* lines of difference (Myers 2015, 15; see also Harding 1986; Haraway 1988). For the purposes of this book, quantum ethnography enables an analysis that inhabits Lyme's multiplicity of meanings and holds them in productive tension.

Learning Lyme

During early conversations with Lyme patients, physicians, and scientists, I described my project as value neutral to assure them that I had no interest in "who was right" and "who was wrong." I soon learned, however, that in the Lyme world, not taking sides is its own form of taking sides. A year into research, the individuals with whom I had spent a significant amount of time would still make the microgestures of someone suspicious of infidelity: a surreptitious sideways glance to gauge my reaction or a pause before responding. Early on, I was often asked, "What's your hypothesis?," which was an indirect way of asking, "Which side do you agree with?" It was a question that also unveiled two interesting social facts: (1) the hegemony of the hypothesis-testing model inside and outside the academy, and (2) the suspicion that academic inquiries are premised on preconceptions. For example, one of my first interviews with a mainstream scientist began with a heated and unexpected reverse interview: "Do you have Lyme disease?" No. "Have you ever had Lyme disease?" No. "No one gets involved in this without having some connection to Lyme. Who is it? Your mom, your dad, your cousin, your friend?" I promise, before I began this project, I did not know anyone who had had Lyme disease. "Well, you better not get Lyme," he declared. "You'll ruin the credibility of your project."

Mainstream physicians and scientists, like the one above, worried for my safety and warned me that "Lyme crazies" might try to hurt me; Lyme patients, advocates, and Lyme-literate physicians expressed concern that just being part of an academic institution that was populated with "chronic Lyme deniers" spelled doom for my project. Irrespective of whether they trusted me or my intentions, they worried that once individuals in administrative positions caught wind of my project, they would put restrictions on what I would be able to say or, at the very worst, make me toe the "party line" that chronic Lyme disease does not exist. For example, even after we had shared two meals together, the leader of a prominent advocacy group declined to be interviewed simply because of my academic affiliation. And one mainstream physician declined to be interviewed because he had Googled

me and saw that I had given a presentation at a community event that was cosponsored by the local health department and a Lyme advocacy group. When one of his colleagues later introduced me to him at a conference, he exclaimed with surprise, "If I had known you were with him, I would have let you interview me! I just figured you were a Lymie!"

Lyme time is measured by these wary advances and retreats. To protect my informants and to preserve the integrity of my project, anonymity was the golden rule. But even under conditions of anonymity, physicians and scientists often felt uncomfortable having our meetings audio recorded, which meant that I relied on my increasing typing speed to capture our conversations. At the end of one interview with a mainstream scientist, the scientist confided, "I'm glad you did it this way [not recording interviews]. I imagine that people were more honest with you." At project's end, I, too, had the sense that, by not recording these interviews, what I lost in accuracy, I gained in depth and "honesty" of disclosure. I also became vigilant about the consistency of my engagement with individuals across the divide to ensure that the way I approached, described, or responded to an idea in conversation was the same irrespective of context. Each time someone asked me whom else I had spoken to or spent time with, I explained why I could not tell them. When I caught myself entertaining the thought that my vigilance was just a self-imposed neurosis, I quickly remembered that these ethnographic parameters were an original function of individuals' nearly ubiquitous concern for their privacy and safety. This concern was most apparent on a day when I conducted multiple interviews at a public health office. The scientist I had just interviewed offered to lead me through the building's labyrinthine structure to my next interview with his colleague. On the way over, we eased into the familiar social territory of benign personal exchange but stopped abruptly before we reached his colleague's open door so that he would not be seen with me. "I'll have to leave you here," he said as he shook my hand and turned quickly on his heels. It was at moments like these that the line between ethnographer and intelligence agent seemed tenuously thin.

The steepest part of the learning curve, however, was becoming proficient in Lyme's language. Because I did not have a natural science or medical background, there was, of course, the new frontier of antibodies and antibiotics, epitopes and proteomics, SPECT scans and PET scans. But more difficult still was maneuvering through the intricacies of how the words used to describe Lyme disease index the speaker's positionality. During an interview with a mainstream physician, I used the word "Lyme literate"

to describe the physicians who diagnose and treat Lyme disease according to the alternative standard of care. This term—or LLMD (Lyme-literate medical doctor)—has become so commonplace that, like "pro-life," its referent displaces its actual meaning. The physician I was interviewing, however, winced as if in pain and told me that he would end the interview if I used the term again. Another physician would not participate in my project until he had clarified how I was using the term "Lyme patient." Was I referring to acute or chronic Lyme patients? I told him that I was referring to anyone who identified as a Lyme patient. He agreed to participate but feared that my eventual audience would not be able to distinguish between "real" and "fake" Lyme patients. Finally, during an interview with a scientist who was new to the field and reluctant to ruffle feathers, we spent a significant amount of time discussing the implications of using the term "post-treatment Lyme disease" versus the term "post-Lyme disease syndrome." At the time of our interview in 2011, mainstream physicians often used the term post-Lyme disease syndrome (found in the 2006 IDSA guidelines) to describe what they believed was a small number of patients who continued to experience symptoms (unrelated to an active bacterial infection) after treatment for acute Lyme disease. Given that much of the debate hinges on whether the bacterium that causes Lyme disease can persist after standard antibiotic treatment, some argued that "post-treatment Lyme disease" was a preferred term because it left open the possibility that persisting symptoms after treatment might be due to persistent infection, while "post-Lyme disease syndrome" foreclosed it. Although, as of this writing, the CDC uses post-treatment Lyme disease syndrome on its website, the use of post-treatment Lyme disease syndrome versus chronic Lyme disease is still understood to reflect implicit support of the mainstream versus Lyme-literate standard of care (DVBD, NCEZID 2019). More than just nosological preoccupation, anxiety over Lyme terminology and its semantic ambiguity is deeply connected to allegiances to particular ways of knowing the body.

During my fieldwork, I found that the division between these ways of knowing the body was reinforced by how Lyme news travels. Time-space compression technologies like Twitter, Facebook, and Instagram have made the idea that news travels fast a banal tautology. But news *does* travel fast across Lyme's electronic etherscape. For example, during my fieldwork, I participated in a panel discussion on the documentary film *Under Our Skin*, which, in following the stories of several chronic Lyme disease patients, has provided a cinematographic loudspeaker for the Lyme community's rallying cry. The panel discussion was hosted at an institution that is widely

understood to support Lyme disease's mainstream standard of care. No sooner was an article about the panel posted to the institution's website than it was absorbed by the rhizomatic tangle of Lyme disease listservs, forums, websites, and blogs, and, within hours of having participated on the panel, I had emails waiting for me in my inbox. This example nicely conveys the paradoxical intimacy of enemy lines. For many mainstream physicians and scientists, "support group" is a four-letter word, a breeding ground for conspiracy theories and antiscience sentiments. For many Lyme patients, mainstream Lyme physicians and scientists are inhabitants of the "dark side," obdurate obstacles to patients' recognition as legitimate sufferers, if not the source of their suffering. But, as the response to the panel discussion reveals, each side is also attuned to the other's Lyme-related activities.

Given this familiarity, it is striking how little communication—let alone personal interaction—actually takes place between Lyme's camps. This was made apparent at a scientific conference I attended. The first evening, I had dinner plans with a Lyme-literate physician. While I waited for him in the hotel's restaurant, a group of mainstream physicians arrived and asked me to join them. I explained that I already had plans and asked if it would be OK for the Lyme-literate physician to join us. "Yes," they replied, before their eyes widened and they looked at each other as if they were only then processing the implications of their answer. When the Lyme-literate physician joined our table, the conversation slowed, and the room felt heavy with the details that had gone unnoticed: the metronomic pulse of the clock on the wall, the edible flower perched on the butter square, the perspiring water glasses, the waiters talking in the corner. One of the mainstream physicians introduced himself, and the Lyme-literate physician replied, "I know who you are," which was to say, "We all know who we are." The conversation haltingly progressed with caution, circumlocution, and subtle jabs. When the check arrived, we rose quickly to leave. The Lyme-literate physician and the mainstream physician who had initially introduced himself walked silently toward the restaurant door, as if neither wanted to be the first to break stride. Upon entering the lobby, the mainstream physician veered off to another section of the hotel, and the two physicians separated, only to return to the tracks of their virtual intimacy.

In the end, the patients and Lyme-literate physicians that mainstream physicians described as dangerous were generous and supportive and welcomed me into their fold. I took it as quite a compliment when one advocate finally exclaimed, "She's practically a Lymie!" And the physicians and scientists whom Lyme advocates feared would silence me were equally generous,

supportive, and welcoming. After I completed my research, I continued to receive emails from individuals across the divide who were curious about the progress of my work and when my book would be published. I am confident that there will be a range of reactions to this text: disappointment and interest, clarity and confusion, validation and exclusion. Any flaws in this book, of which I am sure there are many, are wholly my own. My only hope is that individuals across the divide come away feeling that, at the very least, I attempted to understand and communicate their ideas and experiences as fully and fairly as possible.

Representing Lyme

Even before I finished my research, I became acutely aware of the representational challenges that my project posed. I knew that to maintain the project's integrity—and to avoid the fate of it becoming a casualty of Lyme's controversy—I would have to use utmost care in how I chose my words and represented the ideas and experiences of the individuals with whom I had spent time. In this book, I am interested in knowledge as it is understood and practiced by Lyme patients, physicians, and scientists; I am less interested in knowledge as something that *is*. My interest in facts—scientific and social—only extends as far as individuals perceive or act on them. The choice to represent ideas and experiences in this way is neither an endorsement of certain practices and opinions nor a superficial attempt at even-handedness for the sake of evenhandedness; rather, it is an intentional and intimate engagement with the complicated, interactive, and relational processes of meaning making in individuals' lives.

Of course, one of the implications of a "knowledge as practice," "constructivist," or "genealogical" approach is that it precludes the possibility of being able to answer questions such as, "Does chronic Lyme disease exist?," in any way other than, "It depends on whom you ask."[29] Although this approach is consistent with anthropological and other "explanatory and descriptive" approaches more generally, it nevertheless runs the risk of raising concerns among readers, particularly in the context of contemporary American politics, where conversations about fake news and alternative facts have provoked anxiety about an emergent social reality in which boundaries between facts and beliefs—if not between truths and lies—are blurred (Smith 2006, 3).[30] I hope to convince the reader that what is at work in this book is not false equivalency but an attempt to dig deep enough to reveal the textured and entangled roots of Lyme's bifurcated trunk, to show how,

in the spirit of philosopher of science Ludwik Fleck, the "specific features" of what Lyme patients, physicians, and scientists engage with as "reality" do not precede their engagements but, across time and space, "emerge and acquire their specificity through them" (Smith 2006, 51). In other words, as anthropologist Allan Young suggests, "the ethnographer's job is to stick to reality, its sources and genealogies; that should be enough" (1995, 10).

In this way, I take part in an anthropological tradition of what João Biehl calls the production of "different kinds of evidence," a tradition that is less interested in making normative claims about research participants' ideas and practices and more interested in what happens when these ideas and practices are grounded within a meaningful theoretical framework (Biehl and Eskerod 2007, 405). As a result, I do not hierarchize or take a stance on the different kinds of evidence under analysis but, instead, describe them as fully as possible and, more critically, put these kinds of evidence in conversation with each other. The goal of the book is not to draw conclusions about controversial issues related to Lyme disease but to describe how individuals across the divide understand, experience, and act on these issues to shed new light on the relationship between contested illness, evidence-based medicine, and biopower in the United States.

Along these lines, interlocutors' stories are conveyed as they were told to me. These stories have not been fact-checked or cross-referenced with medical records; rather, they are intended to be read as representations of individuals' lived experience. Furthermore, the terms I use are the terms that individuals use to describe themselves. For example, I use "Lyme patient" to describe any patient who identifies with having or having had Lyme disease, irrespective of their medical history, and I use the term "Lyme-literate physician" to describe any physician who identifies with being a Lyme-literate physician. Although most of the patients I interviewed and observed described experiences with Lyme disease marked by chronicity, I do not make a distinction between chronic Lyme disease and Lyme disease when referring to the ideas and experiences of these patients because most patients and Lyme-literate physicians understand chronic Lyme disease to be one point on the timeline of the Lyme disease experience and not a qualitatively different disease state from acute Lyme disease. Moreover, although patients often refer to themselves as chronic Lyme patients, they also perceive the use of this term by mainstream physicians as a means to distinguish them from what mainstream physicians perceive to be "real" Lyme patients. Because I am only interested in the ideas and experiences of my project's participants, the terms I use in this book reflect the positional-

ity of the individuals who use them, as well as the social contexts in which they are used.

In addition to term use, two other distinctive features of this book are its quotation and citation styles. When quoting project participants, I often include the entirety of participants' thoughts in block quotations. Block quotations, of course, run the risk of diminishing a text's readability; however, because individuals on either side of the divide often felt that their stories had been partially or poorly represented in the past, the importance of keeping participants' voices intact outweighed my writerly impulse to keep quotations short. On the other hand, because this book will likely be read by a range of readers, some of whom will be familiar with Lyme's controversy and some of whom will be learning about Lyme for the first time, I also aim to enhance readability and accessibility by endnoting citations—in addition to discussions about citations—that are related to particularly detailed and esoteric issues. This is the case, for example, in chapter 1, where, in mapping the Lyme disease controversy, I describe and analyze the extensive scientific and medical literatures related to Lyme, a significant portion of which is endnoted.

Finally, in keeping with anthropological representational practices, but particularly because Lyme disease is such a sensitive topic, I have gone to great lengths to ensure participants' anonymity. All names used in this book (with the exception of public figures who did not participate in my project or individuals who were not directly connected to the controversy) are pseudonyms, and I have anonymized stories by removing identifying information, including the locations of most interviews and all observational sites.[31] Because of my commitment to participant anonymity, I chose not to write about some stories and events because I worried that their telling risked exposing participants' identities. And unlike some ethnographies, this one does not include composite characters, a character that comprises features of two or more characters. Although the composite character does offer an ethnographic solution to the problem of participant anonymity, I found that this project's need for transparent representation outweighed the benefits that a technique like the composite character confers. That said, in sections of this book where I quote participants but do not also describe them, I randomly switch participants' gender to provide enhanced anonymity.

Despite the range of representational techniques I use to meet the needs of such a controversial project, it was clear from the outset that these measures alone would be insufficient. Throughout my research, Lyme patients,

physicians, and scientists continually expressed concerns about how I would represent the Lyme disease controversy, and some confided in me that they worried that the end product would be quite different from how I described it. In response to these concerns, and in an attempt to make this project as transparent, participatory, and collaborative as possible, I decided to invite participants to review the dissertation on which this book is based and to provide feedback prior to its submission to the Yale Graduate School of Arts and Sciences in 2014.

The review process occurred in two stages. To ensure that I had protected participants' identities as fully as possibly, I first asked any participant who could be potentially identified in the manuscript to review and approve the section of the manuscript in which they appeared. After this was accomplished, I invited a representative sample of the 145 individuals I interviewed to review and provide feedback on the manuscript, which I uploaded to a private and secure website designed solely for the purpose of participant review. These individuals included ten patients (including patient advocates), ten physicians (half of whom were Lyme literate and half mainstream), and ten scientists. To further protect the privacy of project participants and to ensure that the manuscript was not copied and distributed prior to submission, I required each participant to sign a confidentiality agreement. In total, four patients, six physicians, and four scientists registered to review my manuscript, with the knowledge that, although I would take all feedback into full consideration, I would only be obligated to make changes that were related to concerns about personal identity.

Although inviting one's interlocutors to participate in the representation of their ideas and experiences is becoming an increasingly common anthropological practice, it still gives many anthropologists pause. When I told one of my colleagues about the review process I had undertaken, he replied in an email that he suspected that "transparency" would "serve a diluting rather than an enhancing function." I am happy to report that for this project, the experience was an enhancing one. During both stages of reviews, participants across the standard-of-care divide were eager to help, provided incisive comments and suggestions, and, in their feedback, were notably cautious about suggesting that I change parts with which they disagreed. For example, one mainstream physician, after reading a section in which he anonymously appeared, wrote, "It gave a better appreciation of the anthropological perspective. I don't necessarily entirely agree with you, but then we might not entirely agree about whether George HW Bush was a good president. I found everything to be mostly clear, well written and inter-

esting." Another Lyme-literate physician, after reviewing the entire manuscript, wrote, "Not always 'pretty' (to me) representation of what is going on in 'LymeWorld'—however—honestly reports what your research encountered." He continued, "Like I had hoped of your thesis: honesty & integrity. I'll be interested to learn (eventually) of the 'feedback—or even push-back' you get." I am grateful for the feedback that my interlocutors provided at all stages of this project, but I am particularly grateful for their collaboration with its written form; in the end, it helped to ensure, as much as possible, the accurate representation of their range of ideas and experiences.

Anatomy of a Book

The chapters in this book describe and analyze how Lyme disease is prevented (chapter 2), lived (chapter 3), diagnosed and treated (chapter 4), and biopolitically regulated and legitimated (chapter 5) in the United States. Chapter 1, "Mapping the Lyme Disease Controversy," sets the stage for this discussion by providing an in-depth exploration of the specificities of the Lyme disease controversy and by examining how the controversy is much more complex than a disagreement over diagnosis and treatment. Here, I argue that the controversy can be better understood as the sum of the interaction between Lyme's individual nodes of contestation, which include bacterial species and strains, geographic distribution, vectors and mechanisms of transmission, co-infections, signs and symptoms, pathophysiology, immunization, diagnosis and laboratory testing, and treatment. Drawing from Deleuze and Guattari ([1980] 1987), I use the idea of the rhizome to capture the entangled and contingent nature of the Lyme controversy and to circumnavigate the most common pitfalls—such as teleological assumptions and binary accounts—of representing controversy more generally.

Chapter 2, "Preventing Lyme," fleshes out the environmental dimension of living Lyme disease by examining how individuals across the standard-of-care divide attempt to prevent themselves and their loved ones from getting tick bites. In doing so, the chapter more broadly explores the relationship between individuals' understandings of "nature" and the ways in which they understand and act on their health. As vector-borne diseases like Lyme become an increasing threat in the United States as a result of climate change (Sonenshine 2018), individuals who live in Lyme-endemic areas face the difficult task of negotiating the competing demands between their attraction to nature and their fear of environmental risk. As a result, I suggest that the experience of Lyme disease can be better understood

through what I call an "epidemiology of affect." That is, who gets Lyme disease and why has just as much to do with how individuals *feel* about their natural environment as it has to do with traditional epidemiological factors of risk.

After tracing the historical emergence of Americans' affective relationship with nature, I continue to examine what individuals in Lyme-endemic areas understand to constitute their environment and which part of that environment they find risky in the context of their broader "environmental privilege" (Park and Pellow 2011, 14). I suggest that, for many Lyme disease patients, Lyme disease is just one risk in a constellation of risks that can be broadly defined as a "toxic environment," and I conclude by exploring the range of practices that individuals engage to prevent Lyme disease. I also argue that the incidental effects of tick-borne disease prevention practices—for example, quality time spent between parents and children, intimate time spent between partners, and a collective feeling of greater safety—become just as important to individuals as their perception that the practices they engage *actually work*.

Chapter 3, "Living Lyme," tells the stories of five Lyme patients: a mental health practitioner, a business professional, a teacher, a college student, and a self-described "homemaker." Their stories reveal the striking range of bodily possibilities that being a Lyme patient—and particularly a chronic Lyme patient—entails. In telling their stories, I also analyze what I found to be the most salient themes related to the experience of living contested illness in the context of evidence-based medicine: suffering, survival, and surfeit. By shifting suffering's metric from "mortality to morbidity," this chapter explores the experience of bodily discomfort in the context of social disbelief, disbelief that is compounded by perceptions that Lyme disease is more common among women and that it is an illness of the mind and not the body.[32] In response to their discomfort, patients also enact a range of practices, including the use of complementary and alternative medicine (CAM), which many patients describe as key to their survival. In light of this, I suggest that many patients are attracted to CAM therapies because they perceive these therapies to offer the possibility of *being healed* over and above the possibility of *being cured*. This chapter ends by exploring how individuals in Lyme-endemic areas understand the relationship between wealth and ill health in the United States.

Chapter 4, "Diagnosing and Treating Lyme," explores the experiences and practices of four physicians—two mainstream and two Lyme literate—who diagnose and treat Lyme disease. These stories bring to light the com-

peting and overlapping ways in which mainstream and Lyme-literate practitioners understand and treat the Lyme body; through them, I examine the broader relationship between biomedicine and CAM in the United States and the epistemic significance of medically unexplained illness as a diagnostic category. In this chapter, I suggest that biomedicine makes a fundamental distinction between symptoms and signs as legitimate bases for clinical diagnosis and that this distinction simultaneously generates—and holds in tension—biomedical explainability and unexplainability. In contrast, because CAM does not delineate between symptoms and signs as legitimate bases for diagnosis, illness, by way of symptoms, always has the potential to be explained, a reality that offers some patients with contested illnesses the satisfaction of having their full range of symptoms recognized and therapeutically responded to. I ultimately suggest that, despite their perceived marginality, medically unexplained illnesses are not incidental to biomedicine but intrinsic to it.

Finally, chapter 5, "Lyme Disease, Evidence-Based Medicine, and the Biopolitics of Truthmaking," draws on the example of Lyme's controversy to shed light on both the biopolitical and the biolegitimizing dimensions of evidence-based medicine. I begin the chapter by tracing the historical emergence of evidence-based medicine in the United States and by investigating its relationship to the controversy over whose truths about Lyme disease get to count. Drawing from interviews and conversations with Lyme physicians and scientists, and by closely examining two significant Lyme-related political events, I suggest that evidence-based medicine can be more fully understood as a technology of biopower that organizes and regulates bodies in the pursuit of more "effective and efficient" medicine *and* as a form of biolegitimacy whose power is located in the democratic reach of its affirmation and hierarchization of biological life. I also reinforce the overarching argument of this book, which is that, in addition to standardizing medical practice, evidence-based medicine has had the unintended consequence of amplifying differences in practice and opinion by providing a platform of legitimacy on which *all* individuals—from patients and physicians to scientists and politicians—can make claims to medical truth.

In exploring Lyme disease at the intersection of biomedicine, biopower, and the environment, this book's five chapters make a case for why the rise of evidence-based medicine in the United States has made contested illnesses like Lyme disease even *more contested*. They do so by suggesting that evidence-based medicine has further marginalized contested illnesses

through the formal categorization of medically unexplainable illnesses at the same time that it has opened up a new space in which a range of truths about contested illnesses get to count. If this argument bears weight, it is only because it has been constructed by listening to the stories and observing the practices of those who live Lyme's controversy every day: Lyme patients and the physicians on either side of the standard-of-care divide who diagnose and treat them.