Lyme Disease in Maine
The Science and Stories of an Emerging Epidemic

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ABSTRACT

“The way to look at Lyme is as a spider web, because there are so many threads that become the disease.” –C. Lubelczyk, tick biologist

*Lyme Disease in Maine: The Science and Stories of an Emerging Epidemic* is a multi-disciplinary, multi-faceted attempt to understand the full complexities and controversies of Lyme disease. Lyme disease is the most prevalent vector-borne disease reported in the United States, and it is spreading particularly quickly in Maine. Despite the pressing threat of this epidemic, however, there is a lack of knowledge, urgency, and community conversation about the disease.

In this project, I approached Lyme disease through several lines of inquiry. I learned about the individual and community response through conversation: attending town meetings on tick management via deer hunts, and recording interviews with community members about their experiences as Lyme patients, advocates, medical providers, and interested community members. I grounded these discussions in readings from the scientific literature on the ecology and medicine of the disease, as well as foundational science courses in epidemiology, immunology, and parasitology. My project is titled “The Science and Stories of Lyme Disease”, and throughout the research process, I constantly rediscovered how deeply these two aspects intertwined. Scientific articles and community conversations fed off of each other, and built into my growing understanding of the spider web-like nature of this disease.

I drew on both science and stories in order to share my findings through a long-form narrative science article and a podcast about Lyme disease. These productions cover, broadly, Lyme ecology, the medical response, and what we can learn from the disease. I hosted a Lyme Reception to air the podcast and to provide a space for further community conversation about this epidemic.

Like any epidemic, Lyme disease is a powerful and complex force that shapes human communities. More research and more conversation, particularly with a human ecological focus, are deeply needed in order to better understand this disease, and learn how to respond.
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I can’t remember what my earliest encounter with Lyme disease was, but one childhood experience stands out vivid in my memory. I was at my beloved summer camp, circled up for our daily sing, when I looked at my arm and saw a freckle out of place—then looked more closely and saw it had legs. I felt calm about it—I wasn’t squeamish about bugs in general and was too accustomed to mosquitoes to feel any real outrage at this one stealing my blood. I wandered over to the nurse’s station where a counselor plucked off the tick with a pair of tweezers and put it in a vial for me.

“Tell your parents to give it to your doctor,” she said. “To test it for Lyme.”

I think that vial ended up lost in the drifts of granola bar wrappers and interesting sticks and all the various treasures that accumulate in the bottom of any seven-year-old’s backpack. I’m not sure if my parents ever found it—but doubt they would have worried, if they had. Lyme disease was not a major concern of ours.

Sure, I’d had encounters with the disease. A friend would get it, my grandfather, my mother—and would suffer through a few weeks of antibiotics. The most unfortunate side effects, though, never seemed to be anything worse than the annoyance of a drug routine, and a nasty burn from taking antibiotics and then enjoying the summertime sun. There just weren’t any long-term effects, in my experience. It was a pain, and then it was over.

This isn’t the story of Lyme I know today.

As I grew up, I began to hear scarier stories about Lyme disease. “It was like he had mono, all summer long,” one counselor told me at that same summer camp where I returned to work years later. “My mom stopped being able to use her legs—they think it’s Lyme,” a co-farmhand revealed, as we weeded our way down a row of arugula. “I can’t really eat sugar, or fruit, or gluten, because of Lyme. Those things go straight into my bloodstream and feed the bacteria,” a housemate at College of the Atlantic explained as we oriented each other to our dietary restrictions.

The disease, in these incarnations, was daunting. No longer just a case of test-and-treat-and-recover, it seemed to be showing up in forms that were much harder to diagnose, much harder to treat, and nearly impossible to cure. It was spreading,
too—an epidemic not removed and distant in another country, but here in our own backyards.

I was a little bit afraid, and a little bit fascinated—so I began to ask questions about the disease. I found it unfold into a marvelous complexity, truly the spider web Lubelczyk describes. The threads that become the disease are widely varied, from tick biology to antibiotics, human politics to meteorology, and countless factors in between. To try to understand this web, I’ve bundled the complexities of Lyme disease into three groups: the epidemiology and ecology of Lyme (Lyme Outside); the pathology and medical response (Lyme Within); and some of the responses we have and will have (Lyme In Flux).

When you explore and map these threads, the pattern that emerges is one of a rapidly spreading epidemic, one wrapped in controversy and demanding urgent attention.

PART ONE: LYME OUTSIDE

Epidemiology is, broadly, the study of disease in community. It incorporates disease origin, its incidence, and its spread, all with a view to controlling it in the population. My investigation into the epidemiology of Lyme disease coincided with community meetings in Bar Harbor that were dedicated to the very same topics. The Bar Harbor discussions, though, went by a different name: the Deer Herd Management Plan debates.

One chilly October evening, I made my way to the Bar Harbor Town Hall to attend a special meeting dedicated to this debate. The small room was packed with town members who stood with arms crossed, weight back on their heels—waiting. At the front of the room, tick biologist Chuck Lubelczyk, from the Maine Medical Center Research Institute, prepared his presentation.

The Deer Herd Management Plan was a proposal to allow deer hunting in Bar Harbor in order to reduce the deer population in town. These discussions had stemmed, initially, from a sense that there was a deer problem on Mount Desert Island (MDI). The problem, as stated in the Deer Herd Management Plan, was that deer on the island were at a population well above their social carrying capacity.

Here, classic ecology is invoked. Carrying capacity is a term used in ecology to define the maximum population size that can be supported in an ecosystem before resources run out and the population collapses. A classic example used to explain carrying capacity is rabbit population—these fast-reproducing mammals are a typical story of animals overreaching their carrying capacity. When rabbit
populations explode, the rabbits quickly overeat their resources. At this point, the population plummets as individuals starve to death. Maintaining populations at their carrying capacity is a common goal in wildlife management, since a population that has overshot this level can wreak havoc on the stability of an ecosystem.

But overshooting carrying capacity doesn’t seem to be an issue for deer populations on MDI, though—at least as far as research carried out by Acadia National Park indicates. Were deer above their ecological carrying capacity, researchers would be able to tell by seeing evidence of rampant overgrazing on plants of the park. However, plant surveys indicate, nope—ecologically, deer are at a population density that allows them plenty of food and resources.

*Social carrying capacity* is a different story. This argues that, while deer populations may not be overstressing the environment, they *are* overstressing their human neighbors. What are the indicators of this situation?

According to the Deer Herd Management Task Force, three specific issues are tied up in this. First: there are too many collisions between deer and cars, and that number is increasing. Second: More and more people are requesting nuisance permits, which allow them to kill individual deer on their land in response to property damage done by the deer. And third: Lyme disease is on the rise in Maine. Deer are implicated in that increase, for reasons we’ll come to in a moment.

These trends—increasing deer-car collisions, increasing nuisance permit requests, and increasing Lyme disease incidence—constituted what became known as “the deer problem” in Bar Harbor, and prompted the proposal of a deer hunt on MDI.

The Deer Herd Management Task Force was a group of Bar Harbor residents involved in crafting this plan. They argued that the answer to all three of these issues was simple—lower the deer population. With fewer deer on the island, there would be lessened opportunities for car collisions, nuisance events, or Lyme disease transmission.

Discussions of deer hunting and Lyme disease transmission are closely linked. In examining the feasibility of deer hunt to control Lyme disease, Bar Harbor was engaging in an epidemiological analysis of Lyme, how it spread, and how to control it.

Tick biologist Chuck Lubelczyk’s presentation at the deer hunt meeting focused on control by drawing out the important connection between Lyme disease and deer, mediated through his research specialty—ticks. But this connection requires some explanation, and maybe it’s best to start at the very beginning—or a beginning, at least.
The discovery of Lyme disease traces back to a suburb in Connecticut. In the early 1970s, two Lyme residents, Polly Murray and Judy Mensch, started noticing a strange pattern in the children of their town. Children across their town were complaining of aching knees and summertime flus, and were being diagnosed with juvenile arthritis. This happened over and over again, until this small Connecticut suburb had a juvenile arthritis incidence rate nearly twenty times the national average. Murray and Mensch tracked the pattern with concern, until it was far too strange to ignore. They raised the alarm to state public health officials.

Epidemiologists and public health officials flocked to the area, working to determine the cause of this outcropping of juvenile arthritis. Doctors Allan Steere and Stephen Malawista, from the nearby Yale School of Medicine, led the studies. The task facing them was like detective work, or puzzle solving: they needed to identify commonalities between the juvenile arthritis cases, and track those similarities back to the mystery cause of the disease. These doctors began their work in December of 1975, and spent the winter compiling lists of patients, conducting interviews, and taking blood samples—gathering clues. As Murray and Mensch had noted, many of the children diagnosed with juvenile arthritis had experienced a flu-like fever and a circular rash before arthritis symptoms arose. That was useful information—but the key pattern emerged when Steere and Malawista mapped cases in space and time. Children complaining of arthritis lived exclusively in the wooded parts of town, close to undeveloped fields and stands of trees. There were no cases in the more developed town center. In addition, cases were clustered in time. Reported onset occurred consistently between June and September. Juvenile rheumatoid arthritis is an autoimmune disease, so reasons that would explain it emerging with spatial and temporal clustering are hard to explain.

Steere and Malawista pored over their records. The patterns of disease emergence were consistent not with an autoimmune disorder, but an infectious disease, they concluded—one that, for whatever reason, was more easily transmitted in the summer. Still, this infectious disease was unlike any known bacterial or viral infection. The doctors turned back to the common symptoms, looking for similarities to known diseases. The closest link was the circular rash, which resembled similar rashes that were appearing across Europe and were associated with bacterial infections spread through tick bites. That might explain the seasonal link, as ticks were active in the summer. It might also explain the geographical pattern, too, with cases occurring close to the wooded areas where ticks live.

The real test of this guess would come the next summer. When June came around again, the reports of juvenile arthritis-type disease, often with flu-like fevers and a circular rash began. Now, the epidemiologists added a question to their survey: have you been bitten by a tick recently? A significant number of respondents replied “yes.” This just might be it—ticks could be the causal link of the disease.
With this, scrutiny turned to the ticks of the area. If the ticks were transmitting a bacterial infection, as they did in Europe, the question remained of what this bacterium was. Researchers focused their attention on the blacklegged tick, the species that was present in high densities in Lyme, Connecticut. In 1982, a biologist named Willy Burgdorfer noticed a corkscrew-shaped bacterium wriggling through the tissues of the mashed blacklegged tick he was examining. The corkscrew shape classified the bacterium as a *spirochete*, in a class of bacteria that cause diseases like syphilis. When the blood of patients Steere and Malawista had been investigating was tested, they found a reaction between the patients’ immune systems and the spirochete. This reaction didn’t happen when the blood of people without the disease was tested—and so the disease could be linked to the bacterium. In 1984, the spirochete was officially described as a new species, and was named *Borrelia burgdorferi*, in honor of Burgdorfer.

The pieces were beginning to come together, and the disease could be formally characterized: a *Borrelia burgdorferi* bacterial infection, spread through the bite of a tick, presenting with arthritis and, often, a circular rash and flu-like symptoms. The disease was named after the town where it first appeared, the town where Murray and Mensch lived and made their important observations, the town where Steere and Malawista had focused their investigations, the town that harbored the same species of ticks in which Burgdorfer found the spirochete: Lyme, Connecticut.

### EARLY ECOLOGY

Research into the ecology of Lyme disease had started even before the bacterium was identified. As soon as ticks were identified as disease transmitters, wildlife biologists began to work.

Lyme disease is a vector-borne disease, meaning it’s based on a partnership between pathogen and pathogen-carrier. The pathogen, or actual disease-causing agent (in Lyme’s case, the bacterium *Borrelia burgdorferi*), travels from host to host through another living organism (in Lyme’s case, the blacklegged tick, *Ixodes scapularis*). The classic step in controlling transmission of a vector-borne disease is control of the vector. Without this agent, the disease has no way of making it to and infecting a new host. This is the case for controlling malaria—the mosquito-borne disease is combatted with liberal use of insecticides and mosquito nets. With mosquitos killed and barred from human contact, the malaria microbe cannot access a new host to infect. This is the opposite of “don’t shoot the messenger”—instead, do everything you can to control the messenger, because the message it’s bringing is disease.

This is where the wildlife biologists came onto the scene. They knew that controlling tick populations would be an important step in controlling transmission of this newly identified disease.
The obvious initial research focus was the blacklegged tick itself, explains Chuck Lubelczyk, the tick biologist who presented at the Bar Harbor town meetings.

Lubelczyk is clear in establishing a couple of important biological ground facts about blacklegged ticks, or, to use their scientific name, *Ixodes scapularis*. Ticks are arachnids, related to spiders and mites. They’re ectoparasites, meaning that they rely on attaching to and feeding off of other animal hosts in order to survive. For the tick, this means bloodsucking. To obtain their blood meals, they turn to mammals, birds, and reptiles. When ticks catch the appealing odor of a nearby host, they climb out of the leaf litter and onto the host’s body. From there, it’s a simple task of biting through the skin, covering the area with saliva full of numbing substances and anti-clotting factors, and guzzling away. The tick will stay attached to its host until it’s completely engorged with blood, then drop back into the leaf litter and morph into the next phase of their life. There are four life stages for the blacklegged tick: larva, nymph, adult, and egg. Each stage requires the tick to get a blood meal to pass on to the next stage.

“And the oldest life stage, the adult, is the only stage that reproduces, it’s the only one that lays eggs for the next generation of ticks to start,” Lubelczyk explains. “And for some reason, ticks in the adult stage prefer deer.”

Really, there are a huge variety of hosts the ticks can get blood from— including humans. But deer, for whatever reason, have always been especially noted as the preferred reproductive host. This preference is so strong, blacklegged ticks go by another name, one that may be more familiar: deer tick.

“They require a significant blood meal in order to lay their eggs. So when they get on the deer, they get the blood meal, they drop off—that allows them to lay eggs, sometimes 3000 eggs from an individual tick,” Lubelczyk continues. “So the more deer you have in an area, the bigger the potential for the tick population in an area. It’s simple reproductive biology: you can produce hundreds of thousands of ticks from a single deer.”

Here was a clue for disease control: if ticks were aiding the Lyme bacterium, and deer were aiding ticks. If you could knock out this reproductive host, could you lower tick populations and the risk of Lyme disease?

Researchers began to put this theory into practice, removing deer from study plots in sites scattered around New England. Through fencing deer to specific areas, or hunting to remove them completely, they reduced deer populations. These reductions were extreme, at times lowering the populations to thirty percent of their original size or eliminating deer completely.

For example, take Great Island, Massachusetts. On this small island off of Cape Cod, state biologists were employed to hunt down the deer population. The deer population was reduced by seventy percent over the years from 1982 to 1984.
When the deer population was reduced, the results were as expected—tick population plummeted. As the risk of tick bites declined, so too did the risk of Lyme disease.

The foundation of our understanding of Lyme disease was set: the disease was firmly linked to ticks, and ticks were firmly linked to deer. Or at least, that was the story, then.

But every paradigm changes eventually.

Let’s fast-forward to that night in October, that dusty meeting room. It was 2014, which means research into control of Lyme disease through wildlife management had been going on for forty years. Lubelczyk was speaking at the front of the room, invoking this history of research to describe why a deer hunt in Bar Harbor might help curb the spread of Lyme disease in this community.

In the audience, though, were murmurs of dissent.

The deer hunt was complicated for a number of reasons. For one thing, no one actually knew what the current deer population was on the island. So while they suggested a desirable outcome population, there was no way of knowing when that number would be reached.

For another thing, the area in which hunting would be allowed was fairly limited. Deer could be hunted on privately owned land in certain areas of Bar Harbor, but not in the national park, and not in the central town limits. That left a lot of refuges where deer could go to avoid hunters. It was unclear that the overall deer population would be significantly reduced by a hunt, instead of just redistributed.

And don’t forget— Bar Harbor is a tourist town, an economy dependent on the massive number of people that filter through Acadia National Park each year. Many of these visitors come to see the natural lands and the wildlife, and that includes the deer. And it’s not just tourists. Bar Harbor residents have relationships with the abundant deer as well. There’s one buck, a white 6-pointer, referred affectionately to as Snowball. People know this deer, and don’t want to hunt him.

But there’s one reason that digs deeper than these concerns, that questions the deer hunt at the very core level. Because while there’s research, as Lubelczyk described, that strongly supports the tick-deer relationship to combat Lyme, there’s another way of looking at the system that diminishes the role of deer.

Take, again, the test case of Great Island, Massachusetts. Initially, tick populations dropped when deer population was reduced—but despite the decline, ticks were
not close to extinction. There were barely any deer left on the island, certainly not enough to support the tick population if deer are essential for reproduction. So what was going on?

Michael Good, a local ornithologist and nature tour leader, was in the crowd at that meeting. Later, he talked to me about how the meeting went.

“They got it right that the deer is part of the cycle of Lyme disease, but they’re not the whole story,” he explains.

Turn back to basic tick biology for a minute—or basic Borrelia biology, rather. This bacterium cannot be vertically transmitted in its hosts. That’s to say, it cannot pass from parent to offspring. What does that mean? An infected tick does not lay infected eggs, and does not produce infected young. Every tick that is infected, that carries the bacteria from one host to another, has to first be infected itself.

Tick infection with Borrelia happens, typically, at an early life stage. Remember the tick life cycle? The early life stages, the larvae and nymphs search for blood meals just as later life stages do. However, larvae and nymphs are more likely to attach to smaller animals—mice, shrews, birds, and lizards even.

Many of these animals happen to be able to maintain a level of Borrelia burgdorferi in their bodies. Evidently, it’s an ambivalent relationship: the bacteria remain at a fairly low population; the animal is not bothered by its presence. At least, that’s what the research shows to date.

This relationship creates a sort of steady holding pool for the bacterium. It can exist in these reservoir hosts, and move from there into ticks and then from ticks into a vast array of other hosts. In these other hosts—humans, dogs, the species that display Lyme disease—the bacteria amps up its reproduction. In the reservoir hosts, it maintains a lower, less harmful population. That allows the bacteria to persist in the environment.

One of the key reservoir species is the white-footed mouse, which happens to be particularly abundant, and particularly good at transmitting the bacteria to larval ticks.

So young ticks that feed on reservoir hosts are inoculated with the Lyme bacteria, and carry it on to a series of new targets as it progresses through its life cycle.

Given this, the question of controlling Lyme disease expands to include far more species than simply deer and tick. Good stresses this multi-species mindset. “Controlling Lyme lies with the mouse, and it lies with the tick, and deer are certainly part of that,” he says. “There’s got to be an answer in there somehow.”
Oftentimes, the Lyme ecology discussion is reduced to a “deer or mice” debate. But here’s the thing: deer are important to Lyme disease. Mice are also important to Lyme disease. While deer provide an important resource for ticks to reproduce, mice provide an important key source of infecting the vectors.

As that fact becomes more accepted, it’s realized that the species involved go beyond that, even. Every other species that interacts with the deer and the mice are important, too. What about the hawks and falcons that reduce the mouse population? Or the coyotes that predate deer? Or the plants that dissuade deer from entering an area? When you really start thinking about Lyme transmission, it becomes clear that many species interactions are involved.

“Deer are part of Lyme disease, but so are coyotes, so are fox, so are raccoons, rabbits, birds,” Good lists. “Those have to be understood better.”

Ultimately, this was one of the major concerns with the deer hunt proposed for Bar Harbor. Controlling Lyme disease, residents realized, was not simply a question of controlling deer, or mice—but a question of understanding the complexity of how *Borrelia burgdorferi* moves through the ecosystem. There is no one species that can be controlled, because the fate of any species is closely linked to all of the other players with which it interacts.

“That complicates the whole thing so wildly,” Good reflects. “It’s just not that straightforward.”

To be fair: Lubelczyk, and other deer hunt proponents, are not suggesting that a hunt is a simple, solve-everything solution. He understands that Lyme is acting in an ecosystem, and many species are involved.

But still, he supports the deer hunt. “I look at hunting in this sense as a public health tool, just another tool in the toolbox of combatting Lyme disease,” he says. This disease is such a health crisis that some sort of action is necessary. Research has shown that, in some situations, controlling deer levels has helped—so, he argued, it’s something to try.

Good represents another perspective of this debate. “I started to realize that their logic was wrong,” he asserts, “that we needed to have a bigger discussion about Lyme disease and how we might control it, but that the deer shouldn’t be used as a scapegoat.”

Good’s take on the situation was well represented at the town meeting. I sat there, scrawling notes as different community members stood up and voiced their concerns.

“I don't want to live in a place where there are less than 15 deer per square mile,” one proclaimed. Or, “the town is being run away with by white-footed mice—why
aren’t we focusing on them?” Or “Those deer are just going to run right into the park, and we’ll be no better off.”

Comments quickly turned personal, and Lubelczyk was the target. “You don’t know about that; you don’t live here,” one attendee said. “Why are you using the term deer tick? The right term is blacklegged tick. Are you trying to prove a point?” another provoked.

Lubelczyk grinned through it all, but winces in retrospect. “I kind of harken it back a little to the 1939 Universal movie Frankenstein, where the villagers are there with pitchforks and torches, it was a little animated, kind of came out a little bruised and battered,” he admits.

One thing, at least, was made clear by these impassioned discussions: the Lyme situation was not a simple question. Town members left the meeting with a tangle of information about a truly complex system, but the ultimate question remained in stark black-and-white on the ballot. “Shall the voters of Bar Harbor authorize the Bar Harbor Town Council to petition the Maine Department of Inland Fisheries and Wildlife to adopt a plan based on the Town’s proposed Deer Herd Management Strategy Plan?” it read. In other words: do we go forward with a deer hunt in Bar Harbor? A clear “Yes” or “No”.

ELECTION RESULTS

The plan came to a vote that November. Bar Harbor residents went out to the polls, cast their ballots, and waited for results to be announced.

The next morning, amid a flurry of state news about the re-election of a controversial governor and the continuation of legal bear baiting, they got their results. The Deer Herd Management Plan had been rejected by the people of Bar Harbor. The margin was a slim one—just a 53% majority opposing the 46% in favor of a deer hunt—but as it stood, there would be no prescribed deer cull on Mount Desert Island in the foreseeable future.

Bruce Connery is the wildlife biologist for Acadia National Park and a member of the Deer Herd Management Task Force. He has a decidedly neutral stance on the outcome of the vote. “The way the vote came out is the way the vote came out,” he says, “it was really neither way for me.” He’s not being defensive when he says this: he understood the complexity of the situation and thought it was best to present the situation as fully as he could, and then let the people of Bar Harbor decide.

Still, he has some qualms with the way the proposal was drafted and presented. “I definitely feel we, the Task Force, could have done a better job,” Connery says. He feels the Task Force moved too quickly, proposing a drastic management strategy without the solid data to back it up. “Science takes time,” he insists. Without taking
that time to consider and study the Lyme situation— to collect information on how many deer there were on the island, where they were spreading, whether or not they really aligned with the areas of highest tick density, any number of factors—Connery feels there could be no solid plan of management. “In this scenario I think we needed to use a fine brush instead of a coarse rake,” he says. There simply wasn’t enough time devoted to developing a nuanced management plan based on more complete understanding of the deer situation.

Given the slim margin of the vote and the way hunts have been passed in other Maine communities, Connery finds it likely that this decision will come up again, soon. But with the deer hunt rejected for now, all discussion of further research into the deer population on MDI is off the table.

Connery is disappointed, but not surprised. “We often go away from these situations and don’t follow up. We don’t often say, ‘I don’t want to be caught unprepared next time.’ We walk away,” he says.

This, more than any other aspect of the deer controversy, is what distresses Connery. Because even if he thought the hunt was a rough measure, conceived and drafted too quickly, and proposed to the community without convincing evidence it would work—still, he saw it as a means to getting more data about the deer population.

“Science takes time,” he repeats.

For now, we're back where we started.

**PART TWO: LYME WITHIN**

*BORRELIA IN THE HUMAN BODY*

If any one thing was made clear by the discussions surrounding the Bar Harbor Deer Hunt, it’s that our understanding of how Lyme disease is moving through the ecosystem—Lyme ecology, as we call it—is full of controversies and uncertainty.

As it turns out, those uncertainties about how Lyme is working “out there”, in the woods and environment, are just as present in our understanding of how Lyme is working inside bodies. Looking out, and looking in—Lyme ecology, and Lyme pathology— this disease baffles on both spheres.

Blake Rosso has a particularly interesting view on Lyme pathology. He’s a chiropractor on Mount Desert Island, and a large part of his patient base is made up of people recovering from Lyme disease. Rosso has a special empathy with his patients, because he had Lyme disease himself. His experience with the disease is
actually what convinced him to become a chiropractor, to help others in a similar struggle.

Like many people with Lyme disease, including the initial cases in Lyme, Connecticut, Rosso started noticing symptoms in the summer. He was living and working on MDI, a transplant from his home state of Minnesota. He moved here after graduating from college, working as an AmeriCorps carpenter by day, and exploring the island as a hiker and outdoor enthusiast by night.

“I was working my body pretty good that summer,” he told me. And so when he began to notice the first signs of Lyme—the minor aches and pains, the slight flu—he chalked them up to the effects of youthful exertion. One day, though, mild muscle aches became intense cramping in his neck. He took a day off from work and tried to rest and recover, but within the week, the cramping in his neck had escalated.

“It was no longer just a pain in my neck,” Rosso recalls. “I had zero degrees of rotation. I had to turn my body to enable myself to see side to side.”

The situation got worse, quickly. Soon, Rosso lost his balance, and was suddenly unable to stand straight or walk across a room without support. This lack of physical control spread to his face as well.

“I had facial paralysis that came on pretty strong on the left side of my face,” says Rosso. “I couldn’t even keep toothpaste in. I’d be brushing it’d be falling out of the left side of my mouth. I was like, ‘that’s not supposed to happen.’”

His symptoms weren’t strictly muscular. Soon, he was experiencing heart palpitations, migrating rashes, night sweats, unceasing headaches, anxiety attacks—nearly every system in his body was seizing up, shutting down.

As Rosso now knows, this is not at all uncommon in a typical case of Lyme disease—in fact, he refers to it as a “classic case”. Individuals respond to *Borrelia burgdorferi* infections in different ways, but Rosso’s case seemed to include most of the possible reactions. “I had every symptom in the book,” he reflects.

But at the time, his doctors weren’t able to recognize it as Lyme. “Even when they finally sent out a Lyme test,” Rosso recalls, “they kept saying, ‘This just doesn’t feel like Lyme.’”

This medical response isn’t so surprising, based on the historical understanding of Lyme disease. Remember, the disease Steere and Malawista investigated and identified was characterized by arthritis, a flu-like fever, and a skin rash. Rosso’s case didn’t present this way—his *Borrelia burgdorferi* infection caused mayhem not only for muscles and joints, but also for his heart, brain, nervous system, and digestion. If you go by the original description, Lyme doesn’t seem to fit.
Rosso was experiencing Lyme disease, however—later tests confirmed that. So what is it about this bacterium that allows it to infect a human host and cause such a wide and variable array of symptoms?

**BORRELIA AND THE IMMUNE SYSTEM**

Penelope Houghton has a good understanding of the varied nature of a *Borrelia* infection. She is a naturopath situated just outside of MDI. Nearly half of her practice is dedicated to helping patients with Lyme disease.

“What I always say first is that there’s an umbrella term I’m going to use called Lyme disease, when in fact the organism causing Lyme disease is the spirochete *Borrelia burgdorferi,*” she explains.

*Borrelia,* as we know, travels from host to host through the bite of the blacklegged tick. The bacterial cells enter the tick as the tick guzzles down host blood, then they move to the tick’s midgut and replicate rapidly. When the tick finds a new host and begins to feed, the bacteria respond to the changing chemical environment. The body of a tick that is resting or metamorphosing on the forest floor is a recognizably different chemical environment than that of a tick taking a blood meal from a host. The change in temperature and acidity associated with feeding prompts the now-abundant *Borrelia* to detach from the midgut, burrow into the tick’s body cavity, and travel to the salivary glands. The bacteria express adhesion proteins so they can bind to the tick’s saliva, which is their ticket into the host. When the tick regurgitates as a necessary part of the feeding process, a wave of *Borrelia*-infused saliva washes into the host.

*Borrelia,* now, is faced with an entirely new chemical environment. The host’s bloodstream, in addition to being warmer and more alkaline than the tick’s body, is also swarming with immune cells. These cells, produced by a healthy host immune system, search out the *Borrelia.* On recognizing it, they cover it with encumbering antibodies, or engulf and digest it. It is in the bacteria’s best interest to avoid detection by immune cells, and it has a number of strategies for doing so.

First of all, its shape comes in handy. Like all spirochetes, *Borrelia* is long and spiral-shaped—imagine a corkscrew, or a piece of fusilli pasta. This morphology allows it to move through thick liquids that would stop other bacteria in their tracks.

“They’re built for speed in thick collagenous-type tissue,” says Rosso. “It leaves the blood, and moves into the heart, the cartilage, and the central nervous system because it can move quicker in those viscous fluids.”

These areas are hard for immune cells to access, too. It’s a double-win for the bacteria: not only do they have easier movement in these tissues, they are also protected from attacking immune cells.
The bacteria can make their own refuge, too, changing form to create a durable cyst. In this form, it can’t replicate or move through tissues—but there’s a positive trade-off. As a cyst, the bacterium is undercover, unrecognized by immune cells or antibiotics. When the coast is clear, it can reactivate. Groups of *Borrelia* also create a protein layer called a biofilm that hide them from immune recognition. *Borrelia* has a double-membrane, too, which allows it to disguise its characteristic nametag proteins within an innocuous outer layer. In short, this bacterium is good at travelling incognito.

Even after it’s recognized, the bacteria have tactics to influence host immune response.

A typical immune response starts out fast-and-furious. In this first stage, called the acute phase response, immune cells pump out inflammatory signals at high speed. These chemical signals call cells from all around the body to converge on the *Borrelia*—the result is inflammation, the classic redness and swelling that accompanies most infections. Certain immune cells, called B-cells, adaptively recognize the bacteria and produce antibodies that bind to it. Antibodies flag *Borrelia* so that other cells can engulf them, or load the bacterium with an encumbering cloak. In the first phase of an immune response, these antibodies start out fairly unspecific, binding to the *Borrelia*, but also to a variety of other cells. In a typical infection, the intensity of the immune response diminishes over time. Antibodies become more targeted and more efficient, binding better to the bacteria. This clears the bacteria while allowing the widespread inflammation to calm down. The body, even as it’s still fighting the infection, returns to a healthy state.

This doesn’t happen with a *Borrelia* infection. Inflammation never really calms down, because the bacteria influence the immune response and keep it trapped in the fast-and-furious initial phase.

“Inflammation is such a hallmark. It’s the acute phase reaction, and the body never converts to deal with it as a longer-term infection. This is why symptoms are so terrible in Lyme patients,” says Houghton.

Chronic inflammation is problematic. It’s the core reason behind a slew of human diseases. Crohn’s disease, a disorder causing pain and trouble with digestion, is due to chronic inflammation of the digestive tract. Rheumatoid arthritis is characterized by swollen, painful joints caused by chronic inflammation of joint cartilage. In Lyme disease, this chronic inflammation crops up across many systems in the body—any of those thick tissues where the bacterium makes itself at home—so symptoms are widespread.

This is why the disease can resemble anything from Steere and Malawista’s initial classification—fever as the body initially fights off the infection, a rash as the areas where *Borrelia* is present become inflamed, and later joint pain where the *Borrelia*
moves into the joints and causes inflammation there—to disorders of the musculoskeletal system, the central nervous system, the digestive system, or a combination of all of those. The list of symptoms characterizing Lyme disease is extensive. Intense fatigue? Could be Lyme. Widespread rashes? Could be Lyme. Change in memory, in ability to control your facial muscles, in digestion? Lyme disease, with its multisystem impacts, could account for any of these changes.

So if you have these symptoms, how do you know that *Borrelia* is the culprit?

Nathaniel Hilliard was the first person I interviewed in my quest to understand Lyme disease. I was nervous before this inaugural interview, my first time sitting down to talk about Lyme intentionally, and with a recorder. Hilliard, though, is one of those people with an instantly soothing presence. He’s a gentle soul, a jazz musician, and a longtime pianist. He came to my house, I put on tea, and we sat down to talk about his experience with Lyme disease.

Hilliard’s Lyme experience began, perhaps fittingly, gently. It’s hard for him to say when symptoms began. The summer after he graduated, maybe, but maybe even the spring before? Symptom onset was hard to pinpoint, but it became painfully obvious that something was up by the fall of 2013, when the nagging ache in hands and shoulders became a noticeable trouble. He began going to see doctors—first his general practitioner, then a chiropractor, next a rheumatologist. It wasn’t until six months and nine doctors later that Hilliard was diagnosed with Lyme disease.

This story may sound extreme—six months between noticing symptoms and identifying the disease? — but isn’t so unusual for many of the patients diagnosed with Lyme. To diagnose a patient with Lyme disease, doctors look for evidence that the patient’s body is infected by *Borrelia burgdorferi*. There are two methods, really, for supporting a *Borrelia* infection: symptoms, and laboratory testing.

The gold standard for diagnosing Lyme disease, the rock-solid symptom-based evidence, is presence of the classic bull’s eye rash. Doctors call this *erythema migrans*; it’s a characteristic circular rash that radiates out from the location of the tick bite. The presence of this rash in early cases in Lyme, Connecticut, is what allowed Steere and Malawista to link Lyme to European tick-borne diseases, and it’s remained an important diagnostic tool. If you have the bull’s eye, you’ve got a *Borrelia* infection. But there’s a catch—or several. *Erythema migrans* doesn’t show up in every person with Lyme disease. Current estimates suggest about eighty percent of infected people develop a rash. In Maine, that number has been projected to be even lower. With the rash, you’ve got a solid case for Lyme disease diagnosis and treatment. No rash? Things just got a lot more complicated.

The other symptoms of Lyme disease are elusive, because of their multi-system
nature. Infection causes symptoms ranging anywhere from fever, headache, and joint pain in the early local phase of the infection to chronic fatigue, arthritis, heart conditions, and mental effects as you move into the early disseminated and late disseminated phases. Symptoms vary widely between individuals, and are hard to track in time. It’s challenging, too, to distinguish Lyme disease from a host of other diseases that we don’t fully understand: autoimmune disorders like rheumatoid arthritis and MS; mental health concerns like depression and ADHD; diseases whose causes are still unknown, like chronic fatigue syndrome. Maybe most worrisomely, Lyme disease is often diagnosed as hypochondria, defined as a neurosis characterized by belief that you’re truly ill, even if you are in excellent health. In short, it’s really, really hard to conclusively prove a *Borrelia* infection based on symptoms presented.

In light of this, doctors turn to testing, analyzing a patient’s blood to search for molecular evidence of infection. Testing is a two-step process, an ELISA assay followed by a Western blot. Together, these tests identify the presence of *Borrelia burgdorferi* antibodies in the patient’s blood. If infected with *Borrelia*, a patient’s immune system launches its campaign to search out and destroy bacterial cells and infected cells with the use of antibodies. Finding antibodies to *Borrelia burgdorferi* in a patient’s blood indicates that *Borrelia* is present in the blood, too, and that means Lyme can be diagnosed.

In the ELISA assay, you take the patient’s blood or serum and run it against purified *Borrelia burgdorferi* antigens, those bacterial nametags to which antibodies bind. If you get a reaction, you know your patient’s immune system is making antibodies to the bacterial presence.

In the Western blot, proteins are separated out before testing with an antigen, allowing a more specific test. But again, the core idea is the same: if the test is positive, if the reaction happens, you can conclude that your patient has *Borrelia burgdorferi* antibodies. And where there’s smoke, there’s fire— the bacterium has got to be infecting them, right?

Well, here’s where no matter how much testing you do, you still get equivocal results. The antibodies made against *Borrelia* take several weeks to be detectable in the bloodstream. In the case of Lyme, antibody levels often peak more than two months after onset of symptoms. Running a Lyme test before this point is likely to return a false negative, despite true infection with *Borrelia*. Besides which, patients with compromised immune systems might not be making enough antibody for the test to pick up anything at all. And if the bacteria goes incognito, antibody production slows, resulting, again, in unidentifiably low levels of antibody despite the presence of *Borrelia*. Changing the test to decrease the levels of antibody needed to return a positive response would result in other infections more easily showing up as positive Lyme result—it’s a tricky balance to strike, and the current ELISA test does not manage it well.
“That screening test only picks up thirty to sixty percent of cases—it’s a very poor screening test. This is why almost fifty percent of people who have Lyme are being told they don’t have Lyme, because the screening test is the first step. That’s alarming,” Houghton cautions.

It’s worth noting that what would be useful, in this case, would be a direct test for presence of the pathogen itself, rather than having to look for evidence of the immune response. Proof that the *Borrelia* bacterium is swimming about through the bloodstream. For other diseases, blood cultures and PCR analyses allow this, letting us look specifically for the pathogen rather than relying on evidence of an immune response.

For Lyme, we just aren’t there yet. At this point, the conventional medicine community has to rely on what we have to positively identify the disease: *erythema migrans*, various elusive symptoms, and unreliable testing. The process of diagnosis is long and anything but straightforward.

That causes many patients to turn to non-conventional methods for a Lyme diagnosis. A non-conventional diagnosis can take different forms, ones that rely more on intuition than on stark evidence of infection.

Houghton and Rosso have encountered this situation many times.

“It’s kind of like a pattern recognition process,” Houghton explains. “Medicine is in general, but in this case especially. If you see multi-system symptoms, sometimes an abrupt change in the person’s health status, usually no known tick bite...you just begin to fit these puzzle pieces together.”

Laboratory testing and the presence of key symptoms are still useful for diagnosis, but ultimately it’s the combination of many different puzzle pieces of evidence that illuminates the disease.

“You just sort of have a feeling of, ‘This is a strange assortment of things.’ That’s not a very clinical way of putting it, but you almost have a feeling of ‘Lyme’,” Houghton says.

Hilliard’s doctor had a similar feeling when diagnosing him with Lyme. The doctor, a naturopath, followed the two-step testing process—but when the screening test came back negative, continued on to the Western Blot anyways. That test came back positive: Hilliard’s Lyme diagnosis was confirmed.

But diagnosis is only the first step in a long road of Lyme treatment.
The difficulty of diagnosing Lyme feeds into the difficulty in treating the disease.

The first tactic for combatting a *Borrelia* infection is generally uncontested. Upon removing a tick engorged with blood, at the moment a rash appears or any Lyme-like symptoms appear, a patient is prescribed with a twenty-one day course of an antibiotic like Doxycycline.

Some doctors will prescribe antibiotics even before the onset of Lyme symptoms, before any tests have been sent out to confirm or deny a *Borrelia* infection. This is called the prophylactic dose, and it’s increasingly common practice in Lyme endemic regions.

The hope is that the antibiotic will attack the bacteria when it’s at its most vulnerable, moving through the bloodstream in the first phase of infection. But killing all of the bacteria is a tall order—and if antibiotics were prescribed too late and the infection progresses, treatment becomes more difficult. The same tactics the bacteria use to evade a host’s immune system help it to evade the treatment prescribed by doctors. Antibiotics have just as hard a time accessing the thick tissues *Borrelia* invades as a host’s immune cells do. Similarly, encysted forms of the bacteria are as hard to target with classic pharmaceuticals as they are to remove with natural immune function.

But treating Lyme disease becomes a question of more than just biochemical cause-and-effect. Debates on how to treat this disease have caused a schism in the medical community.

Roughly, there are two groups of doctors that treat Lyme. The split rests on, ultimately, the challenges involved in definitively proving the presence of *Borrelia burgdorferi* in the patient’s body. As we’ve seen, this inability to prove bacterial presence makes diagnosis complicated—the difficulties in treatment are closely tied to the same issue. This uncertainty has led to a broad schism in the medical community—those that believe in persistence of *Borrelia* in the body following treatment, and those that say solid proof of long-term infection following proper treatment does not exist. The potential persistent infection has been named Chronic Lyme Disease, or CLD.

To be clear: the side of the medical community that does not accept the notion of CLD is not ignoring the persistent symptoms involved in many Lyme disease cases. But they make an important distinction, and call these symptoms Post-treatment Lyme Disease Syndrome, or PTLDS. The difference, here, is that these health care providers do not believe there’s evidence of *Borrelia*—because as we’ve seen in the case of diagnosis, that evidence is really hard to pin down—and so purport that continuing to prescribe antibiotic treatment targeting the bacteria is ineffective.
Conventional doctors are vetted by medical boards, organizations that oversee a doctor’s practices to ensure that good medical care is being provided. The guidelines used to judge a doctor’s treatment practices are called the Standard of Care. They are compiled by groups of doctors and researchers, like the Infectious Disease Society of America (IDSA), drawing from the best scientific data available for any given ailment. Doctors that are certified by medical boards are bound to comply by these standards.

The Standard of Care for the treatment of Lyme disease, as it’s described by IDSA, recommends the classic dose of twenty-one days of Doxycycline, or another antibiotic, for people that have a reasonable chance of having Lyme. If Lyme-like symptoms don’t subside over twenty-one days, the patient can receive a limited additional dose of antibiotics. The Standard of Care for Lyme disease does not espouse belief in the existence of CLD. Lingering symptoms following a course of antibiotics is identified, instead, as PTLDS. In short, the IDSA guidelines say there’s no way of proving a continuing, active *Borrelia* infection. Continuing antibiotic treatment will do no good, the standards say, and may in fact have negative side effects for the patient.

There’s some evidence, however, that patients complaining of persistent symptoms improve when they continue to take long-term antibiotics—prescribed to them against the standard of care. This is anecdotal evidence, meaning it’s based on analyzing individual. It’s enough to lead a vocal group of doctors to say that CLD really exists. The proof is in the pudding, they argue: patients improve with continued antibiotics; therefore the bacteria must still be present in the body in these long-term cases.

Medical boards, though, set their standards on “evidence-based medicine”. That means anecdotal evidence is not enough. It needs to be corroborated by randomized, controlled trials—the time-honored methods for determining treatment efficacy—in order for the standard of care to change.

At present, if a doctor decides to act against those standards and continue to prescribe antibiotics based on the anecdotal evidence, they are taking a big risk. “Medical doctors’ hands are really tied,” says Houghton, “because they’ve got these standards of practice, and they have their associations looking over their shoulders. If they prescribe long-term antibiotics, their license is at stake.”

However, there’s another group of health practitioners that are not compelled to comply with the Standard of Care. You could call these alternative medicine providers, or homeopathic doctors, or naturopaths, or chiropractors—but ultimately they are linked in their freedom to act outside of oversight by a conventional medical association. For alternative doctors who identify as “Lyme-literate”, this allows them to diagnose active, persisting *Borrelia* infection—and prescribe treatment based on that diagnosis.
And it gets more complicated, too, because many doctors that do believe that CLD explains the lingering symptoms felt by Lyme patients also believe that a non-antibiotic approach would suit the patient best. Their treatment eschews antibiotics and ultimately aligns better with the board standards—even though their ideologies diverge.

This is a situation where the controversy of Lyme disease stands out stark and contentious. Based on the diagnostic tools available now, conventional medicine boards are leery of affirming a persistent presence of *Borrelia* in the body. But anecdotal evidence of patients responding well to continued antibiotics leads many doctors to continue to prescribe these drugs regardless of the standards. This controversy has seeped into the medical literature, into reports made to the government on the state of Lyme, into courtrooms where doctors are sued for malpractice.

If you’re confused, at this point, you aren’t alone. There are strident voices that speak convincingly on every side of this debate, and it’s hard to know what to believe. But the fact of the matter remains: whether it’s to respond to a persistent active *Borrelia* infection or lingering post-treatment symptoms, a patient still requires treatment for their complaints. So how do you move forward?

**LYME TREATMENT**

Homeopathic doctors like Rosso and Houghton are “Lyme-literate” medical providers, and they strongly believe that the root cause of the symptoms is a continuing *Borrelia* infection. That’s challenging to prove, they realize—but they’re convinced by their personal experience. Treatment based on the core belief of a persistent *Borrelia* infection has helped their patients heal, Rosso and Houghton profess, so of course they’ll continue to treat that way. As alternative practitioners, they are not compelled to follow board standards, and their treatment takes a different emphasis.

Rosso follows a general framework for treatment. “There’s three big things,” he explains. “Build the body’s systems up from within, introduce an anti-spirochete compound, and open up elimination channels.” This framework is a multi-pronged approach to removing *Borrelia* from the body. For a lot of people, it’s a refreshing approach. Many of his patients have already tried the piecewise, symptoms-focused approach to treatment recommended by medical boards, Rosso says—and haven’t found much luck.

Houghton agrees. “These patients are often really at the end of their rope by the time they’re coming in here,” she explains. Following a non-conventional treatment plan helps many heal.

“It’s thought that you’re never really cured of Lyme,” Houghton explains. “But I think
they can be—even if what that really means is that they are living in a copacetic way with the bacteria.” To reach that point of balance is the goal of non-standard approaches to treating Lyme.

The whole-body approach to treating Lyme requires the patient’s full investment, as Houghton and Rosso emphasize. Despite this focus on patient self-advocacy, treating Lyme is still challenging for doctors. Part of this is due to the tricky nature of the disease, but part is due to the lack of “Lyme-literate” doctors. Those that do believe in CLD and treat accordingly are flooded with patients looking for help.

“I would say probably half my practice deals with Lyme patients now,” explains Houghton. “And sometimes I wish that wasn’t the situation, because they're complex cases. As a naturopath, I’m used to complexity—but still, doctors that treat Lyme are completely overwhelmed.”

“As a practitioner, dealing with Lyme patients is extremely hard,” agrees Rosso. “Most people treating Lyme right now have had the disease themselves, and that’s how they get into it. It’s this empathy, and it’s so rewarding because people get their lives back—but we need more of us.”

Maybe this is an achievable future. There appears to be some increase in understanding of Lyme disease going on in the community.

For Rosso, the situation has changed since he struggled with Lyme disease. “The worst thing when I was sick was that nobody knew what was going on,” he reflects. “Nobody could tell me what was going on. It was so dark. No one would want to talk about it—none of the practitioners around here, whether they had the knowledge or not. There were just no answers, none on this island.”

He left the island to attend chiropractic school in the Midwest, and returned to the island to open his practice two years ago.

“When I came back to the island,” he says, “I found a Lyme community here. It’s this amazing collection of people who have been through this and are working on it together and educating themselves. That’s great, and that’s growing. Things are changing.”

PART THREE: LYME IN FLUX

Emily Bracale is well-aware of the Lyme-related changes going on in herself and her community. She contracted Lyme disease, she believes, sometime in her mid-
twenties. Her twenties and thirties were decades full of mystifying, untraceable symptoms with no known cause—like Rosso's story, but extended over decades.

I met Bracale at her home in Bar Harbor to speak with her about Lyme disease in this community. As it turns out, I'm not alone in this. After Bracale finally received a Lyme diagnosis and treatment, she began to pour herself into helping others navigate the Lyme experience. She is, as she says, the unofficial Lyme orienteer of Bar Harbor. This position keeps her busy.

“I meet with about three or four people every week,” Bracale reflects.

Bracale's busyness alone points to the prevalence of Lyme disease on Mount Desert Island, but the data back up this impression. While there are no specific counts of new Lyme cases on this island, Lyme incidence quadrupled in the whole of Hancock County between 2009 and 2012.

Living with ticks, and with the fear of Lyme disease, seems to be the new norm on MDI. “When someone says, ‘Oh, I haven't found a tick on my kid,’” Rosso muses, “You have to pause. You don't hear that often on this island.”

In light of this new normal, Bracale has an important role to play. As orienteer, she connects new Lyme patients to doctors, teaches her own techniques for responding to Lyme flare-ups, and shares her own art and stories about Lyme. Bracale is passionate about this work, and driven to track down more information about Lyme. After we spoke, she sent me article after article, a relevant court case, a recorded talk. She's resourceful in her response, too, trying everything from Reiki to antibiotics to gathering roots of Japanese knotweed to make an anti-bacterial tea.

With a finger on the pulse of Lyme disease in Bar Harbor, Bracale is also keenly aware of how Lyme has changed her own lifestyle.

When asked if Lyme—both having it, and simply knowing it’s out there—has changed the way she enters into the woods, she responds, “Absolutely.”

She showed me a painting she created before being diagnosed with Lyme disease. It shows a wooded path, curving gently through yellowing trees.

“As a landscape painter, it was typical for me to take a little stool into the woods and do a whole painting. I’d sit in the woods, off the path, so that hikers could pass me,” she explains. Now? “I tend to choose carriage paths, well-groomed trails, beach walks—places where I can walk without brushing into any grasses or any shrubbery.”

By avoiding brushy areas, Bracale is lessening the chance that a hungry tick, perched on a blade of grass or a shrub, will catch on to her as she passes by.
Avoiding brush is a relatively easy adjustment to make, but it points at a wider change. Lyme threatens. Ordinary walks become events where you need to be vigilant about where you move.

Gone are the days, for Bracale, of an intimately close physical relationship with the woods. "I would take a sleeping bag and go lay down in the Great Meadow and just rest there," she reminisced as we looked at her woodland painting. "And now I look back and just go, 'Oh, my god! Wow, that was really fun but I hope I didn't get exposed that day, again!"

Rosso’s story strikes a similar note. "Before I got sick," he says, "I was out there, off the trails, going through the back country as much as you could on this island. Now—no way. I'll stick to those trails."

It's an evocative reminder that Lyme is affecting us in more ways than are first apparent.

“That thought that you can't get out and immerse yourself in this world anymore, it's terrible,” Rosso muses.

Luckily, there are simple changes that can be made for self-protection from ticks. Tick biologist Chuck Lubelczyk spends his typical workdays scouring the woods for ticks, collecting them by the hundreds to maintain population estimates and to send back to the lab for testing. As far as he knows, Lubelczyk has never had Lyme disease. So how does he avoid it?

“When I go out into the woods, I tend to dress well,” he says. Dressing well for tick protection means long pants, tucked into socks and tall boots. “If you wear something over the cuff of your pants, that’s the first line of defense,” Lubelczyk explains, as it blocks ticks crawling from the leaf litter. When these clothes and boots are permeated with insect repellents and insecticides—so much the better, in terms of dissuading ticks.

And even if you do get bitten by a tick, you may have some time. It's estimated to take at least twenty-four hours for a tick to transmit Borrelia after biting a human host. If you find and remove the tick in time, your chance of infection drops.

But ticks are tiny, especially as larvae and nymphs. Finding them is like finding a poppy seed in a handful of sand—except the poppy seed is also actively trying to evade detection. Ticks tend to crawl to hidden, protected places on the body—the pant line, armpit, groin, that space behind the ear. Tracking down these ticks requires careful full-body examinations. Enter: the tick check.

“Of course you do tick checks,” Lubelczyk says. “You do them as soon as you come in, and you do them religiously. You kind of get used to it as a lifestyle thing.”
When scaled up, a lot of these same tactics can be applied to the landscape level for, in theory, the same effects.

While individuals can avoid brushy areas frequented by ticks, communities can remove brush and replace it with clear, wide walking paths. Homeowners or property managers can remove brushy, tick-promoting plants, like Japanese barberry, and replace them with tick-deterrents like lavender or geranium plants. The same goes for plants that deter deer, too, in the hopes that keeping deer out of an area will block one major tick transportation route.

Insecticides have been suggested as a landscape-wide Lyme control tactic, as well. It's reasonable to balk at the prospect of spraying broad areas with insecticides, but tick biologists have developed methods to target these insecticides—or acaricides, tick-killers specifically. One popular strategy is soaking cotton balls in the acaricide Permethrin and placing them in white-footed mouse dens, thereby killing any ticks the mice may carry. Another, more elaborate technique, caters to the deer lovers who recoil at hunting. Instead of being hunted, deer are lured by enticing salt licks into four posted structures. As they squeeze to access the salt, they rub against the posts and have Permethrin applied to their fur and skin. The ticks are killed, but the deer live to lick another day.

Synthetic chemicals are not the only option. In fact, one developing method of tick control uses the parasitic relationship that ticks use on us—but this time, the ticks are the ones being parasitized. In this case, the parasite of the parasite is a fungus, Metarhizium anisopliae. A Metarhizium spore will germinate on the surface of a tick, then grow long hyphae that insinuate themselves deep into the tick’s body. It kills the tick within a few days, and uses the cadaver as a nutrient source to produce new spores that will go on to infect more ticks.

No matter the method, landscape-wide efforts to reduce tick populations point to the effect Lyme has on the entire community. Lyme is not a disease that only affects the outdoor enthusiasts, the rugged hikers, the landscape painters who immerse themselves in the woods.

“Contrary to what most people think,” Lubelczyk cautions, “most people get tick bites around their homes. Not from going out hiking, not from backpacking, not from biking, fishing, whatever— most people get it from right around their home areas.”

This isn’t a disease that targets a narrow population—it’s a disease to which we’re all susceptible.
That susceptibility becomes ever-more clear as Lyme disease spreads into new areas and increases in incidence—rapidly.

Houghton reflects on this ruefully. “I remember when I moved to Maine. It was eleven years ago. When I knew I wanted to move to the East Coast, I thought ‘Well, I want to go where there’s no Lyme disease,’ so I chose Maine—little did anyone know at that point!”

Little did anyone know, Houghton means, that Maine would rapidly become one of the states with the highest rates of Lyme disease in the country. In 2013, Maine ranked behind only New Hampshire and Vermont in terms of Lyme incidence, with 84.8 cases per 100,000 individuals.

The situation in Maine is similar to patterns seen across New England, across the Eastern Seaboard, and stretching into the Midwest. Maps of disease incidence show red hotspots in the New England, where the disease was first recognized, that expand out to cover most of the northeastern and mid-Atlantic states, as well as the northern Midwest. In more recent maps, spots appear in California, in Texas, in Washington—the disease is present and recognized in an increasing number of states.

The core question, then, becomes: why is it spreading?

When I posed this question to my interviewees, I received a variety of responses. The truth is, no one can say for certain why the disease is expanding, and asking that question leads into a bewildering rabbit hole of responses. Lyme is spreading for every reason from bio warfare to the American diet. These suggestions have some validity, and deserve further investigation.

But ultimately, this is a disease spread by ticks—so the reasons for its spread that align with the spread of tick populations seem most immediate.

Broadly, the reasons seem like they can be split into two categories: climate, and human movement.

Climate, defined as the temperature and precipitation patterns of a region, plays closely into tick survival. Ticks are dependent on a certain amount of moisture and a certain temperature range in order to survive. When conditions get rough, they move beneath the forest floor, which is kept insulated and moist by the layers of leaves above. Temperature and precipitation levels that fall vastly out of the acceptable tick ranges can kill them, even in the protection of the leaf layer.
Climate affects far more than individual tick survival; it also determines what resources are available to ticks. This occurs in a myriad of ways. For example, take the Lyme-acorn connection drawn by ecologist Richard Ostfeld. Ostfeld, in studying Eastern forest ecology, found that mouse populations tracked closely with the cycles of oak tree acorn production. See, acorns are expensive for an oak tree to make—so oftentimes, an oak will wait for several years and produce more acorns rather than producing only a few every year. When trees align on the same cycle in response to climate cues, there are acorn boom years in which the ecosystem is flooded with a resource that’s usually scarce. Mice are sensitive to this change, eating tons of acorns and using those resources to produce more offspring. The year following an oak-boom, therefore, exhibits a mouse boom. Ticks, hungry for mouse blood, make the best of the opportunity—and the number and prevalence of infected ticks jumps.

That alone makes Lyme transmission to humans more likely, but it gets worse: acorn booms are not sustained from year to year. The overabundance of mice from the previous year is missing the bumper crop of acorns to sustain them, and much of the population dies. That leaves ticks without a sizable body of hosts—but unlike the mice, the ticks don’t perish. Or, even if some of them do, others turn to alternative hosts, including humans. So a bumper crop of acorns one year can lead to more infected ticks seeking out human hosts the next year.

This connection is just one example—climate plays into Lyme disease in a multitude of ways, triggering changes in point species that feed up and out into the entire ecosystem.

If climate is involved, so too must be climate change, the human-induced alternation of long-standing patterns of temperature and precipitation. Climate change is instating a new set of general climate measures across the globe. In the northeastern USA, climates are becoming more variable from year to year, but with a general shift to warmer temperatures.

These temperatures can shorten the winter season, allowing more time for ticks to be active and hunting. With more time, there are more opportunities for humans to be bitten and infected.

Another impact of climate change is the increase of dramatic and unpredicted weather patterns, such as last winter’s extreme abundance of snow. This variation, these harsh conditions do not necessarily hinder tick populations. For example, the snow of last winter, rather than killing ticks over the winter, actually insulated the leaf litter, keeping them warm and secure.

And again, climate change impacts not only the ticks but also the species on which the ticks depend. With changing climates comes changing distribution of plants and animals. Certain plants abet tick survival, so as they spread to the warming climates of the north, so too do ticks.
Human movements and actions are the other key part of this overall spread. Regardless of climate, humans are moving more and more into wilderness areas. As populations grow, cities expand out in sprawling suburbs. These suburbs replace old-growth forest habitats with fragmented forests and new growth. The complex structure and ecology of the forest is divided into smaller patches. These patches have lower species diversity and more edge habitat.

This affects Lyme in several ways. The loss of species diversity can remove controls on reservoir species populations. For example, a white-footed mouse can live easily in a small forest fragment; its prime predator, the red fox, struggles. Along with this, forest edges favor sun-loving, brushy plant species—and this in turn aids ticks, who don’t do as well in deeper coniferous forest, where leaf layers are replaced by less-insulating pine needles.

The development of suburbs also brings humans into close daily contact with these fragmented ecosystems. Lubelczyk notes, “As we move into areas where we like our greenbelts, we like our nature preserves—I like seeing deer, foxes in my backyard—we also move into areas with some unwanted aspects, and namely the parasites that feed on those animals.”

With that close relationship to parasites comes an unfortunate relationship to the pathogens they carry—and transmission increases.

So, for the myriad directions and countless tangles into which this question of, “how does it spread?” leads, it’s still an important one to pursue. Because maybe if we determine key factors in the spread of Lyme disease, we can begin to slow its explosive growth—not only here in Bar Harbor, but in other Lyme-endemic areas...

CONCLUSION

...and of course, this is where the conversation began.

Controlling the spread of Lyme through manipulating key factors was precisely what Bar Harbor attempted to do with the proposed deer hunt. On first glance, that was an unsuccessful process, a devotion of time and energy that resulted in a simple rejection without much forward progress.

But maybe there was more gained from this process than just that.

“During the deer hunt talks, I started to realize we needed to have a much bigger discussion about Lyme disease,” says Good, the Bar Harbor nature guide.

Connery, Acadia wildlife biologist, echoes this sentiment, calling for a continued conversation. “If you don’t challenge an idea once in a while, or test it,” he says,
“then you’re going down a scientific process that isn’t really being full. You’re just accepting what someone else came up with, rather than doing what science is supposed to do, which is ask questions and then challenge those questions.”

Lyme disease, at this point, is undoubtedly full of questions to challenge. Points of controversy are speckled across our understanding of this disease, from how the disease moves through the ecosystem, to how it moves through the human body, to how communities should respond. And as these topics are examined, they unfold into ever more complexity and, always, further questions.

That complexity is key. Understanding this disease as fully as we can is crucial to responding to it as individuals and as a community. And as one of a host of emerging infectious diseases, the Lyme disease situation may be a harbinger of what’s to come.

The goal is not to inspire fear of the woods—it’s to talk, and investigate, and learn, so that we can learn how to respond. In responding to an epidemic, we are forced to use what we know and make decisions on the run—but that only encourages the persistence of active and critical reflection, and of education that reaches as many people as it can. Above all, it demands more conversation and discussion about the disease, how it operates, and how we can respond. This is the work of tick biologists, Lyme advocates, doctors, natural guides, community members— all of us, because Lyme touches all of us, and all of these perspectives play into the complex nature of the disease.

As Good puts it, “We need to change the way we think about and approach Lyme disease. We have to look at it from a broad community perspective.”

We need start the conversation, now.
2. THE PODCAST

Title: Lyme Conversations
*An exploration of the science and stories of Lyme disease in Bar Harbor.*

Intro: Lyme Conversations
Run-time: 2 minutes

**Episode 1:** Deer Hunts, Deer Ticks, and the Ecology of Lyme Disease
Run-time: 25 minutes
Description: Ellie and Zabet begin the conversation about Lyme disease, focusing on disease ecology through the lens of a deer hunt debate.

**Episode 2:** Lyme in the Body
Run-time: 31 minutes
Description: In Episode 2, Ellie and Zabet talk about how the Lyme bacterium works in the body, the troubles with diagnosing Lyme disease, and the medical response.

**Episode 3:** Learning from Lyme Disease
Run-time: 19 minutes
Description: In Episode 3, Ellie and Zabet talk about how Lyme disease is changing the way we enter the woods, and the way we think about health. Is awareness and conversation really enough of a response? Maybe there’s something to be learned from these epidemics...

Podcasts can be accessed on the digital version of this senior project. They are also now available online via Bandcamp and Wordpress (lymeconversations.bandcamp.com/releases and lymeconversations.wordpress.com).
On May 20\textsuperscript{th}, 2015, Bar Harbor and COA community members gathered on the back
4. DOCUMENTED SOURCES

Recorded Interviews
1. Nathaniel Hilliard, Lyme patient and COA alum (21 January 2015)
4. Chuck Lubelczyk, Tick Biologist at Maine Medical Center Research Institute (11 February 2015, 13 April 2015)
5. Emily Bracale, Lyme patient and advocate, and COA alum (18 February 2015)
6. Penelope Houghton, naturopath at Acadia Naturopathic (3 April 2015)
7. Blake Rosso, Lyme patient and chiropractor at Rosso Chiropractic (6 April 2015)

Supporting Coursework
1. HKU01x Epidemics (FA-14, online course)
   Description: This 10-week online course, offered by the University of Hong Kong through the online learning organization edX, provided an overview of epidemiology. Class content covered the history of epidemiology, the origin and spread of disease, and the prevention of epidemics through research and public health measures. Content was delivered and discussed through video lectures, readings, quizzes, and discussion forums.

2. Immunology (WI-15, Tutorial)
   In this tutorial, five students worked with mentor Ileana Soto (Jackson Lab research associate) to develop a foundational understanding of immunology. The course followed the Kuby Immunology textbook to cover the cells and organs of the immune system, innate and adaptive immune responses, and immune disorders. My final project focused on the immune response to *Borrelia burgdorferi*.

3. The Ecology and Evolution of Parasites (SP-15, Tutorial)
   This course was a student-driven exploration of the vast diversity of parasites and how they operate in ecosystems. The course used narrative science writer Carl Zimmer’s text on parasites, *Parasite Rex*, as a framework, and delved more deeply into topics raised by the text through supplemental reading and discussion of the scientific literature.
Bibliography


Cary Institute of Ecosystem Studies. (2015, February 18). In a warmer world, ticks that spread disease are arriving earlier, expanding their ranges. Cary EcoFocus Newsletter. Web.


Lyme Disease in Maine: The Science and Stories of an Emerging Epidemic
(Senior Project Proposal)

Eliza Oldach
Project Director: Helen Hess
FA-14

submitted: September 17, 2014
Title:
Lyme Disease in Maine: The Science and Stories of an Emerging Epidemic

Description:
How do humans interact with their environment? This is one of the broadest and most fundamental questions of studying human ecology. I am interested in a particular sort of interaction—the relationship between humans and natural ecosystems in the presence of disease.

Emerging infectious diseases are prevalent enough in the world today to warrant an acronym (EID). By definition, an EID is an infectious disease that has recently become prevalent in human populations, and is slated to increase in coming decades. In an undisturbed ecosystem, infection rates are checked by the limited number of hosts available to a pathogen and an evolutionary battle between infector and infected. As humans increasingly encroach on these previously unexplored ecosystems, pathogens are exposed to new potential host in abundant numbers. The typical result is a host-jump for the pathogen, and then rapid increase of infection in the human population. EIDs are some of the most prevalent and devastating diseases on the planet, and include viruses like HIV, SARS, and West Nile. We are now in a period of widespread perturbations on ecosystems, through development of wild land, urban sprawl, and climate change. These patterns of anthropogenic impacts on natural systems result in more and more opportunity for EIDs.

This summer, I watched the unfolding of the Ebola epidemic in western Africa with wide and frightened eyes—Ebola is a virus that has typically jumps to human populations through contact with infected fruit bats and proceeds to spread rapidly through human populations. This was impressed on me with overwhelming emphasis as I followed the spread of the epidemic this summer and fall.

EIDs are not confined to far-off lands and distant news reports, however. There are local examples that, if not as dramatically cataclysmic, cause relatable distress for humans. Lyme disease is a key example of this. This disease, caused by a bacterium transmits to humans through the bite of an infected tick, is an emerging epidemic in New England. Infection rates of this disease have risen rapidly in the past ten years alone. It is a disease that is hard to pin down, and nearly every aspect of its study is a source of debate among scientists, medical providers, and patients. Identifying infected patients is difficult, as current tests frequently return false positives or negatives. Responding to an infection with antibiotics is effective—sometimes. Other times, the antibiotics only add to a long list of troubles for a patient who is already facing the neurological and muscular challenges of infection. Medical professionals disagree on the existence of chronic Lyme disease, let alone the best methods for treating affected patients. The ecology of the disease is also widely contested. A reservoir host provides a pool for the disease to exist in an ecosystem, but it is unknown whether the white-footed mouse or the white-tailed deer, which host ticks at different life stages, is more crucial to the ultimate transmission of the disease to humans.
A field so full of debate and so locally present calls out for further investigation. There is a richness of opinions and perspectives here, and an abundance of stories from people who have been affected, first-hand, by the disease. I want to probe this topic, drawing from my background in ecology and increasing my familiarity with anthropology to understand the role of Lyme in shaping human interactions with the wild.

My project will rely heavily on my experience in the hard sciences. At UC-Davis (my original college) and COA, I have focused academically on ecology. Courses that have been particularly influential include, at UC-Davis, Ecology, Genetics, and Marine Ecology, and, at COA, Invertebrate Zoology, Evolution, and Wildlife Ecology. I have spent two summers conducting field ecology research projects, experiences which have both drawn from and enhanced my coursework in ecology. As a result of this academic past, I feel well prepared to study the ecology of Lyme, to work from primary literature and gain an understanding of how the disease moves from host to host, and how human perturbations on the New England forest ecosystem have resulted in this emerging disease. Having a background in the hard sciences will also help my investigation into general epidemiology and the medical side of Lyme infection, topics I will explore through an online course and more primary literature research.

However, there is a much more indefinite side to Lyme disease as well, and to focus only on what can be described in the hard science conventions would be to leave much of the story missing. As part of my study of this disease, I want to speak to people who are personally impacted. There are a multitude of voices to be heard—national park directors responding to the bacterial threat, herbalists and conventional physicians working to help patients heal, patients themselves combatting the disease and its dangerous symptoms. When I bring up Lyme disease in conversations, everyone has a story to tell. Though I have little experience in anthropology, I have always loved and craved stories. In my senior project, I want to balance my hard science training with the human side of the disease. The human stories will not be supplements, human-interest extras, but a crucial part of understanding the full scope of the disease. These stories, these people, these struggles are just as important to hear and have just as much to offer. Indeed, this balance between hard sciences and human stories, this recognition of the necessity of understanding each, is something I have strived to attain throughout my education at COA. Courses I have taken in literature and art will be just as instrumental in helping me to understand the full scope of Lyme disease, and EIDs in general, as my more conventional studies in the hard sciences.

In the research aspects of my project, I will benefit enormously from the local awareness of Lyme disease. My research has already begun: I attended the Lyme Symposium held right here at COA last spring. As I continue, I will draw from resources at Acadia National Park, Maine Medical Center Research Institute, local healthcare providers of both conventional and unconventional practices, and people who have had personal experience with the disease. Connections made in past courses, particularly Wildlife Ecology collaborations, will be instrumental in feeding my research. In addition, conferences like the upcoming Lyme Symposium at
Massachusetts General Hospital will allow me to connect with researchers that are also examining these issues at local and global scales.

I have mentioned, now, multiple times, my goal of “understanding Lyme disease” in all its facets. That goal is important, but personal. Just as field ecology research projects gain their full value when they are shared with the broader community, I will need to share any understanding gained in order to have a complete project. This sharing ties into the balance between hard and soft science that I am seeking in this project, because it requires blending knowledge of the ecology and medicine of Lyme disease with human reactions and stories. My final product will draw from two terms of research—one largely based in hard science research, the other focused on collecting human stories—to present a relatable story about local Lyme disease in light of global EIDs. I will craft a story to share what I learn with the local community. These stories will take two forms. The first is a long-form article, the sort that would be publishable in a popular science magazine or blog. This form will allow me to build from my past experience in writing, a method of communication that has come the most naturally to me in the past. A long-form article has the benefit of being easily distributed in print and online to people interested in Lyme disease in Maine. In addition to a written article, however, I also want to craft an audio story. I am drawn to this largely because of podcasts like This American Life or Radiolab, productions that layer voices of all perspectives on a topic to provide the listener with a full story and a strong sense of the people involved. There is power in hearing a story, whether it be scientific or medical or personal, and collecting audio recordings of the people I speak with throughout this project will provide a wealth of voices to share. There is a very practical, public health aspect to this part of the project, as greater education about Lyme disease can help people prevent infection. The hearing and sharing of these stories is also important to this community—Lyme disease is established now, a part of our lives in New England, and giving space for these stories is important to our community identity and sense of place, our role as humans living in and interacting with the environment around us.

**Academically Engaged Hours, Goals, and Final Product:**

I will divide my senior project time into one credit per term, and have organized the outline of my research and project production around this time division. Each term will have 2 concrete deadlines for submissions to my project director: a Term Plan due in the first few weeks and a Term Report due at the final week.

**Fall Term: Ecology and Epidemiology of Lyme Disease**

Goals: In fall term, my senior project will resemble a scientific research project. This will have two main foci: the ecology and the epidemiology of Lyme in Maine. For my research into the disease ecology, I will focus on reading primary literature about the organisms involved in the cycle and transmission of Lyme here, especially in case studies and experimental studies on how host abundance impacts human infection rates. I will meet with Acadia Park officials like Bruce Connery and Maine
Academically Engaged Hours: 1 credit, 150 hours

My research will be spread out over the course of the term. Much of this research will be book- or internet-based, but other forms of research (conference attendance, meetings with experts) will have different time requirements. To complete 150 hours of academically engaged time Fall term, I expect to spend 10 hours a week conducting book- or internet-based research (this time includes reading sources and compiling a report of my findings), and about 50 hours over the course of the term attending conferences, meeting with local experts, and meeting with my project director for check-ins and guidance.

Time Table:
- September 17: Term Plan due (project proposal)
- September 24: Epidemiology course begins
- November 8-10: Lyme Symposium at Massachusetts General Hospital
- November 21: Term Report due (organized compilation of research findings)
- December 2: Epidemiology course completed

Winter Term: Collecting Human Perspectives

Goals: During the winter term, I plan to meet with people who have personal experience with Lyme disease to conduct interviews and gather audio for my final project. I have plans to speak with several students on-campus, as well as the experts previously mentioned. I also want to focus, during winter term, on the current debate on Lyme disease treatment. In order to gain more insight into this debate, I will speak with both conventional medical providers and non-conventional medical providers to hear how they conceptualize the disease and help their patients in responding to it. Specific people I hope to speak with include Chris Marano of Clear Path Herbals and Blake Rosso from Gerrish Chiropractic. Both of these men spoke at the Lyme Symposium and offered their views on varying methods for treating Lyme disease.

Academically Engaged Hours: 1 credit, 150 hours

Much of my time winter term will be spent working directly with people through sitting down and speaking with them. Following a recorded interview, I expect to spend a lot of time editing the recordings, transcribing them, and beginning to craft interviews into the final podcast-style audio show. Learning how to use sound editing software will be a high time investment. I expect to spend about 50 hours learning about ethical interviewing practices, interviewing people, and processing...
interviews, 50 hours learning audio software, and 50 hours organizing interviews and continuing research from fall term over the course of the term.

**Time Table: January 5-March 15**
- January 12: Term Plan due (people to interview and continued research goals)
- February 27 (Week 8): Logistics for staging podcast hearing in spring term decided
- March 13: Term Report due (transcriptions of interviews, first draft of podcast complete)

**Spring Term: Crafting the Final Product**

Goals: My final product will be created and shared during spring term. During this term, I will continue to edit and adjust recordings from the winter into a polished audio story. I will spend a large portion of the term writing, turning reports and notes from research conducted in the fall and winter into a piece of creative nonfiction. During this term I will also share my final products, through organizing “hearings” of the podcast I have created and distributing the article. I would be interested especially in sharing my research with visitors to Acadia, and will reach out to Acadia officials about avenues for this. Given the importance stories from members of the COA community, I think it will be important to share the podcast on-campus as well.

Academically Engaged Hours: The majority of my time spring term will be spent writing and revising the long-form article. I expect to spend 60 hours over the course of the term writing and revising, 50 hours completing the podcast, and 40 hours organizing how to share the works (researching avenues, determining logistics, submitting the article to essay competitions, etc.).

**Time Table:**
- April 6: Term Plan due (logistics for podcast hearing, writing schedule, and plans for article submission)
- May 1 (Week 4): First draft of article submitted to reviewers
- Mid-term: Host podcast hearing at COA
- May 22 (Week 7): Final draft of article complete
- May 29: Senior project completed—podcast has been shared, article has been completed and revised and submitted for publication

**New Learning:**

Gaining and sharing an understanding of Lyme disease will require, first, an independent education in the broad fields of disease ecology and epidemiology, requiring me to craft and adapt a plan of study in order to cover the topics I will need. For this work, I will draw largely from my background in ecology and my completion of past research projects for science classes, as these experiences have taught me where to look for information.

The interviewing process will require more outside help. I will need to learn how to conduct these conversations in an ethical and thoughtful way, especially when discussing personal and, at times, traumatic experiences with disease.
Besides the ethical considerations of interviews, I will need to learn the technical side of using sound recordings. I have crafted stories out of research before (in presenting research projects to classes and at symposia), but never in a purely audio form. Using sound editing software will be an essential in order to complete this project.

**Role of the Director:**

Helen Hess will be the director of this project. She is an invertebrate zoologist, and is knowledgeable about parasitology and has a demonstrated interest in EIDs, making her an excellent resource for providing guidance as I study a tick-borne disease. In addition, she has worked with Acadia National Park on research projects and can help provide contacts with people to interview there. I will seek her assistance especially in fall term, to keep me on-track with my independent research in fall term. Meeting with her on a weekly basis will provide some of the structure and accountability I need in order to maintain my research trajectory and not be distracted by smaller side topics. I also believe Helen has an understanding of the balance I am seeking in my final products, based on our mutual appreciation for science communicators like David Quammen or Carl Zimmer. Periodically, I will consult other professors for advice in my project (for example: Heath Cabot to provide me with some guidance for conducting interviews; Karen Waldron to help me craft a balanced narrative), but as official director, I will meet with Helen throughout all three terms of the project.

**Criteria for Evaluation:**

- Creation of a podcast-type audio story; sharing of this podcast through a local hearing.
- Creation of a long-form article; sharing of this article through local channels and creative nonfiction magazine submission.
- Record of research carried out over the course of fall and winter terms (including certificate of completion of Epidemiology online course).
- Thoughtful adaptation of the project from the initial plan throughout the course of research and interviews.
- My evaluators should also look carefully for the balances I am trying to achieve in my project: between a global perspective and a local investigation, between a variety of research sources, and between the hard sciences and the human story.

**Bibliography:**

**Books**
- *Spillover*, David Quammen
- *Rats, Lice, and History*, Hans Zinsser
- *Lyme Disease: The Ecology of a Complex System*, David Ostfeld

**Journals and Reports**
- *Emerging Infectious Diseases*, published by the CDC
- *Tick-Borne Diseases on Islesboro: The Problem, The Causes, The Solutions*, report created by the Town of Isleboro Tick-Borne Disease Prevention Committee
-recent publications from the Maine Medical Center Research Institute Vector-Borne Disease Laboratory

Organizations

- MMCRI: Vector-Borne Disease Laboratory (contact: Chuck Lubelczyk, vector ecologist)
- Acadia National Park (contact: Bruce Connery, wildlife biologist)
- World Health Organization (website)
- Audacity, for sound editing software and suggestions