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Non-Fiction | FALL 2018

## Listening to Lyme

By Merissa Nathan Gerson

My spine hurts. My right ankle hurts. Sometimes I'm moody, tired, angry, rude, annoying, annoyed. Sometimes I eat a lot of sugar and sometimes I see ghosts and sometimes my right pinky toe stings. My nails are painted yellow, I get thirsty in the night, sometimes my heart races and on full moons I tend to cry, want sex, and overeat.

According to my math and to the breadth of my understanding of spiral syphilis-behaving bacteria, and the presence of some collection of antibodies, all of the above could be a result of, symptomatic of, or indicative and causal and products of Lyme disease. Lyme disease is an expensive disease, approximately \$1-2000 per infection, and that's for the test alone after insurance. Everyone and their mother has it here, where I live, on an island that shuts its boats down for storms. You don't have to roll in a field or milk a cow or shoot a pig between the eyes. You don't need to be knee deep in tall grasses while skinning and de-feathering a once alive chicken in order to catch this disease.

No. The ticks, it seems, that are the cause, which can be debated, because who knows how the world turns and why diseases reappear in the dead of winter unless the bed is lined with ticks because the doctor said, "new infection," and "let's check your antibodies," and since you already took a lot of amoxicillin this month you are just going to have your cake, eat it too, and avoid chicken killers and high grasses and those that slaughter swine for the time being.

Yes. Lyme is alive and well in your blood, my blood, our blood, this island's blood. This is the Lyme Colony and we shut in here and are slowed down to a pulp, to a slow ooze, thanks to swollen knees and encephalitis of the knuckles and palpitation of the heart. Lethargy, paleness, a lack of inertia or a proclivity to spin towards the bed – this is the disease we speak of. Bee sting therapy may or may not help. Long term memory loss is an option.

Like I said, we can't know for sure if stubbing one's toes regularly is a symptom of this disorder. If you like pink foods or small babies or if you are interested in climbing trees or running for president, it might be this disease. If you find yourself being cruel or yelling out or writing rants about everyone you grew up with on Facebook, gaining weight, beating strangers – again – Lyme disease can be to blame.

They discovered mine in New Orleans where I was holed up in bed with swollen knees. No walking. No looking for houses. No buying property or beignets. Instead I was shipped back to the island, back to the colony, to slow down with my contemporaries and bear the mark of an island circled by its own band of witches and fog, gods and ghosts. Yes, they took me in on

a boat and taped me to a bed and said, “drink” of the evil elixir called doxycycline, which like the slaughterers goes into the throat and then takes over and destroys the belly. If Lyme caused you pain, the war in your large intestines between the right of bacteria to live, and the right to die, this might destroy you.

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Todd Rogers heard last night that I have Lyme. We were sitting on a couch at the local community center and his eyes were dark and beady and he said I should be really careful. This was after I asked why he wasn't drinking and he said it was because he had Lyme and for 8 months was on a cocktail of drugs. He spoke on a horror movie level of his own experience, the 28 pills a day he took including two kinds of antibiotics and the fish oil, the vitamin D, and the diet shifts. "You need," he told me, "to be scared." "You need," he told me, "to go to the hospital Monday morning and ask for the Igenex test and then you need to go to the local Lyme Center, find out what strange you have, and address it."

“This is very serious,” he said.

I tried to tell him what I did know, or what I was doing, but there was no room for my narrative. This was about his horrifying experience, not mine – despite his desperate attempt to warn me. He didn't know about my two Western Blot tests or about the antibiotics research I did, or why I wasn't on doxycycline and how I chose the alternate antibiotic after extensive research. He didn't know I met Porochista Kakhpour over the weekend and he also didn't know I was already filled with fear.

What he also didn't know was that I was already consulting someone and had the herbal remedy of the Gods, an expensive and total system flush, on hand. He didn't know about my consultation, or my probiotics, or my current Whole30 cleanse or about the fact I am taking two magnesium pills, three potent multivitamins, and 3 vitamin C supplements a day to keep myself afloat.

Todd's verbal invasion, coupled with an absurd question asking if I had picked up this strand of Lyme when I was in Uganda, was one of many boundary crossings that Lyme has afforded me. It has invited fear and advice into my life, and also, chemicals. This is my third treatment of antibiotics since May. I eschewed Western medicine before that, healed my depression and my titanium bolted spine through diet shifts and non-invasive chiropractors, through spiritual and financial guidance. I hit a wall, though, when Lyme, which I apparently had for years, appeared in my life.

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My right hand aches. I decided I can feel them hatching in my veins. Last night Noava, who is pregnant, told me about her mother and the bee sting therapy she uses for her aching muscles. Every other day she is stung by bees to activate her cortisol.

My head hurts. I feel flutters in my chest and I am having throbbing in my neck. Is it because I am paranoid, or is it Lyme? Is it the spirochetes or is it because I am Jewish, waiting for my eradication?

Today at the café a Jewish woman didn't believe me when I said there was more white supremacy and anti-Semitism here than anywhere else I have ever lived. "Oh, it's everywhere, you just weren't paying attention." It was a lot of energy, maybe that was it, maybe her incredulous speculation at the possibility of being unwelcome where she lives, maybe that up against my insistence stirred the sleeping entities in my blood. Maybe she ghost whispered to the dead in my veins, and the living, and now in my own home I am gasping for Lyme breath.

Is it the water that stopped running? Is it the lack of exercise or spring on the horizon or is it the woman who said I need more education, after my two Master's degrees, to move forward in my career?

My wrists still hurt. I still have heart palpitations and a headache. The Nor'easter has destroyed the water system in my house. It comes on and off at its own whim. I am on an island. I am surrounded by water on all sides. There is water boiling in my kitchen. My veins, said John F. Kennedy, are filled with salt. I am, he said once, of the same makeup of the sea.

What it would take to lie down and listen, whisper with the spirochetes? Would they tell me to remove a limb? To write a book? To become a lesbian? Would they ask me if I was crazy or maybe confess to me that they themselves were overtaking my mind? Am I a colonized entity? And is it the pills or is it the tick? Which one is the colonizer? Which is the colonized? I am a medical subject all over again only there is no narrative and there is no witness and I have no disease, I mean Lyme, I mean Rocky Mountain Spotted Fever, I mean.

Lyme brain is a thing, where thoughts are staccato and memories are void. I do forget things. I don't handle my freelance load as well as I used to where everything returned to my head in due time. I don't trust me as much. I worry about cancer and heart attacks and insanity, about being evil or wrong. I have a therapist and a doctor and a healer and a chiropractor and a team of rabbis and I am still afraid because I am not with myself, I am looking to them instead of me for answers. Because I feel at the whim of the Lyme, in me an unknown I cannot conquer.

There are things living in my thighs. In my belly. In my neck and mouth and collar bone and according to my cousin my headaches this week are the result of the spirochetes dying. It causes pain, apparently, when the colonizers die. Now what?

Sometimes at random I call out for my mother. I live in a house alone in the woods that belongs to her and in the silence, the eerie pre-storm silence I can almost not stand to be with myself, itching, desperate to leap out of my own skin.

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**Merissa Nathan Gerson is an errant student of Narrative Medicine based on the island of Martha's Vineyard. Her writing on disability, sexuality, Judaism, and inherited trauma, appears in The New York Times, The Atlantic, Playboy, Elle and beyond and she was the inherited trauma consultant to Amazon's hit show, Transparent. Merissa is a current ELI Talks 2018 Fellow and founded [www.KenMeansYes.org](http://www.KenMeansYes.org), a rape prevention initiative urging clergy to speak up and out about consent. She has Lyme disease and Rocky Mountain Spotted Fever, among other problems.**