

from Leslie Feinberg August 2011 transgenderwarrior.org
my research notes on the medical politics driving the "Lyme Wars"

Introduction

It has taken me two years to gather this information about medical politics surrounding the Lyme epidemic. My health has made reading and writing so difficult that all I can do is to post some of my personal research notes arranged in the most readable form I can manage.

You won't find medical information in these pages. But you will find links to sources that do include medical facts about Lyme.

For information about the seriousness of the epidemic, you can view/hear the award-winning documentary "Under Our Skin." Free clips are available at the documentary's web site and on youtube. (underourskin.com)

For a checklist of the kind of symptoms that emerge as patterns, you can consult page 9 of Dr. Joseph Burrascano's online document "Advanced topics in Lyme Disease: Diagnostic hints and treatment guidelines for Lyme and other tick borne illnesses." (ilads.org/files/burrascano_0905.pdf)

My research notes that follow present information that, I believe, raises important questions about the debate that currently rages as to whether lack of adequate treatment for Lyme and its co-infections (Lyme/+), and the seriousness of this epidemic, requires further scientific research.

I have no personal agenda in the medical debate between what are two major contending scientific viewpoints.

I was not cured after taking the two to four weeks of oral antibiotics that the ruling U.S. medical establishment recommends. But I cannot afford to even attempt long-term intravenous treatment for Lyme/+ that the other medical viewpoint holds is necessary, particularly for late-stage Lyme/+ infections like mine.

I recall the bulls-eye rashes on my legs—now known to be one symptom of Lyme spirochete infection--some three and a half decades ago, before there was medical knowledge about Lyme disease. I went untreated until recently.

My laboratory tests light up for Lyme, as well as co-infections, including Babesiosis and Bartonella. The validity of Lyme tests is often debated in this medical struggle. My treatment, therefore, has to proceed based on physical evidence. For example, Babesiosis is similar to malaria, and treated with the same medications. When I experience persistent fever, soaking sweats (night and day) and teeth-chattering chills, I get better when I take anti-malarial medication.

When I take antibiotic protocols aimed at treating Lyme and Bartonella, every one of my symptoms related to those diseases improve with the first doses. But my treatment has been too

little, too late. I get quantitatively better, but the symptoms return quickly as soon as I'm off the medications.

I take an impartial position where medical issues are concerned. But when it comes to medical politics that hold back further scientific development and understanding, I take a strong, anti-capitalist position.

My posting this series of research notes on the web may lead some to hope that I am feeling better, and able to communicate online or by e-mail. In fact, it's just the opposite.

Posting this information allows me to put down a great burden: I am in physical agony from these infectious diseases, and the toll they take on me is progressing overall. The resulting disabilities have made three of the tasks I faced seemed insurmountable.

The first was the enormous amount of legal protections necessary to put in place because institutionalized state discrimination would have granted biological relatives--hostile strangers--powers to make decisions regarding my life and death. The second task was the labor required to create my "screened-in" photographic series, art made to document my disabilities resulting from Lyme/+.

The third work I needed to finish was this writing about the medical politics holding back scientific understanding about Lyme/+.

I had wanted to write up this material in my own words with elaboration of my own thinking on this issue. Instead, I am posting these research notes. I thank each researcher whose work I cite for their valuable labor, and particularly extend my solidarity to those who did their work while ill. While I and those quoted do not necessarily share a common worldview, we are all demanding answers that the facts and questions surrounding the Lyme/+ epidemic well deserve.

I had hoped to write much more about how ruling classes have historically used already existing prejudices to deny the scientific resources and individual aid that epidemics require. I had wanted in particular to write more about institutionalized racism, women's oppression and other barriers to health care, about the infamous "Tuskegee experiment" and the AIDS epidemic.

I had hoped to write about how denial of medical care for Lyme/+ forces individuals to buy drugs in the illegal, exorbitantly expensive, underground pharmaceutical industry. And I wanted to point out the hypocrisy of denying antibiotic treatment to those who are suffering in this epidemic, while the food industry pumps antibiotics into the food chain for profit.

I had wanted to write about my own experiences in Cuba, where I went with people who were ill to hospitals in three instances. In each case the treatment was free, and the ill individuals didn't even have to sit down for a moment to wait to be seen by doctors. I wanted to convey the gist of discussions with hundreds of Cubans as I walked through the city of Havana at night, too ill to sleep. For those who want to read about Cuban health care, I refer you to my already published series: "Rainbow Solidarity in Defense of Cuba," which can be found online: transgenderwarrior.org

With this posting of these notes, I must accept that this is the best I can do. Putting some of this research together in a readable form has taken a great toll on my health. I must turn now towards palliative approaches to my care.

At this time I am so ill, I can't answer questions, or discuss or debate this material. If I've made factual errors in citations, I apologize in advance and ask you to correct them in your own future research.

I do hope to be able to post my photographic "screened-in" series in upcoming days and weeks. However, if that effort takes an additional toll on my health, I will ask for help in uploading the photographs. I offer all of my photos to you as personal gifts, under Creative Commons copyright (cite attribution/location; no derivative use; no commercial use):
[flickr.com/photos/transgenderwarrior/sets](https://www.flickr.com/photos/transgenderwarrior/sets)

To understand why I have felt so driven to complete these tasks, I offer this quote from Che Guevara: "At the risk of seeming ridiculous, let me say that the true revolutionary is guided by a great feeling of love. ... We must strive every day so that this love of living humanity will be transformed into actual deeds, into acts that serve as examples, as a moving force."

Next: Casualty of an undeclared war