

# VANITY FAIR

Q&amp;A

## **Q&A: The Lyme Disease Controversy**

by *Frank DiGiacomo*

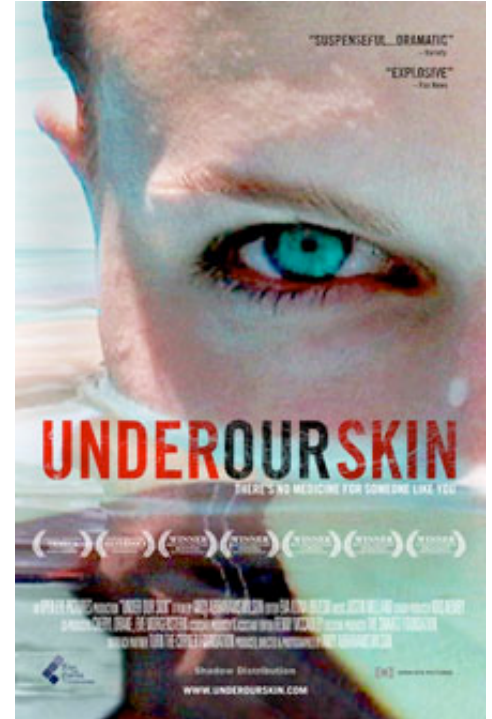
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If there's a subject that's guaranteed to start my wife and me bickering like Elizabeth Taylor and Richard Burton in *Who's Afraid of Virginia Woolf?*, it's Lyme disease. In the late 1990s, after a summer spent covering the Hamptons for the *New York Observer*, I was overcome with overwhelming fatigue, blinding headaches, an acute sensitivity to light, joint pain and, eventually, intensely creepy muscle spasms and heart flutters that made me feel like I had a baby alien nesting in my chest. My doctor was convinced that I had contracted Lyme disease even though he could find no tick, no telltale bulls-eye rash, and the blood test came up negative. (Current Lyme tests have a high false negative rate.) After a three-week regimen of very strong antibiotics, I felt my old self again save for the still-palpable fear that I might somehow contract the disease again.

My wife harbors a very different opinion of my illness. She finds it hilarious that I claim to have contracted a debilitating disease in the posh Hamptons—especially since I can't produce any medical proof of my affliction. Her reaction used to make the big veins in my forehead throb—until I saw Andy Abrahams Wilson's fascinating documentary on Lyme disease, *Under Our Skin*, which opened in limited theatrical release in New York last Friday, expands to Los Angeles today and a number of other cities in July. By the end of the film, I understood that my wife's skepticism was hardly unique, and, more importantly, that I'm one of the lucky ones. Wilson, who's based in San Francisco, does an artful and compelling job of illuminating some very dark aspects of this disease, which, in addition to being remarkably difficult to diagnose and treat, is a subject of considerable controversy within the medical establishment. According to the official definition of Lyme put together by the Infectious Disease Society of America (I.D.S.A.)—guidelines that insurance companies use to determine what treatments they cover—chronic Lyme disease does not officially exist, meaning that Lyme specialists who insist otherwise sometimes risk their medical careers to treat their long-suffering patients. But that's not the only revelation raised in *Under Our Skin*. One researcher uncovers a possible connection between Lyme and such perplexing neurodegenerative diseases as Multiple Sclerosis (M.S.), Alzheimer's disease and Amyotrophic Lateral Sclerosis (A.L.S.). Even more chilling is the movie's disclosure that a majority of the I.D.S.A. Lyme panel members had potential conflicts or undisclosed financial interests in companies that, for instance, were developing Lyme vaccines and tests.

A few weeks ago, Wilson discussed these and other startling aspects of his film with me. He also took issue with a March 2007 [Forbes magazine story](#) that deals with some of the same doctors mentioned in *Under Our Skin*. Judging from the film's performance over the weekend in New York, I'm not the only one with questions about Lyme disease. According to a spokeswoman for *Under Our Skin*, the film sold out many of its Friday screenings and did a very respectable \$7,100 on a single screen for the weekend. Now, if I can only get the wife to see it.

**Frank DiGiacomo: There are moments when *Under Our Skin* felt to me like an episode of *The X Files*. I**



**knew Lyme disease was controversial, but I was completely unaware of the politics surrounding the definition and treatment of the disease.**

*Andy Abrahams Wilson:* Well, I was a big fan of *The X Files*, so I take that as a compliment. As a matter of fact, one reason that I was initially attracted to this issue is a conspiracy theory that the bug that causes Lyme disease was actually engineered as a biological warfare agent. There's a whole book dedicated to this theory. It's called *Lab 257* [Subtitle: *The Disturbing Story of the Government's Secret Plum Island Germ Laboratory*, by Michael C. Carroll]. Lab 257 was, or is, an animal research laboratory off the coast of Long Island. There was even a Nazi doctor who was hired to run the lab after World War II, and he had previously worked on biological agents using ticks as possible carriers. And Plum Island is right across the sound from Lyme, Connecticut, which is Ground Zero for the disease. So, there's a lot of circumstantial evidence, but we weren't able to find the smoking gun so we didn't even include this in the film, but that certainly piqued my interest in the beginning.

**I was going to say, despite my *X Files* analogy, there's nothing outlandish about *Under Our Skin*. There are no mad scientists in the film, just a lot of really sick people and questionable medical politics. Were there any other factors that led you to make the documentary?**

I had no idea how serious it was until a friend of mine here in the Bay Area was diagnosed with M.S. and then A.L.S., which is a death sentence, basically, and then, finally, Lyme disease—and it was only then that she started to get better. I was shocked that Lyme disease could do that. I was shocked that it was out here in California, because there's an assumption that it's an East coast disease, and that it had such a severe neurological impact. The more I looked into it, the more I uncovered untold numbers of people who were completely falling through the system and had the same story: not being diagnosed or being misdiagnosed; not being taken seriously; not being treated and not being covered for treatment because officially chronic Lyme disease doesn't exist.

**There's a researcher in your film who discovers that there might be a connection between Lyme disease and Parkinson's, M.S., Alzheimer's and A.L.S.**

For me, that was one of the most alarming and fascinating aspects of this issue, and why this is a life and death issue. We may not know people who are diagnosed with Lyme disease, but we all know people who have been diagnosed with one of those autoimmune or neurodegenerative illnesses. And if there is a connection, then that would transform medicine as we know it.

**Have you shown your film to any of doctors and scientists who are involved in the research and treatment of A.L.S., M.S. or Parkinson's?**

One branch of our educational campaign is to reach out to the medical establishment, which is going to be very resistant. I mean, we're challenging medical orthodoxy. So that's why I've always believed it's not about convincing the medical establishment. It's about creating the demand from the bottom up. The good news is that. I've had people say, 'The film saved my life.' They saw the film, and they got the diagnosis and the help that they needed.

**You report that Connecticut Attorney General Richard Blumenthal was investigating the Infectious Diseases Society of America's process for writing the 2006 guidelines for the definition of Lyme disease because, as you point out in the film, a number of the I.D.S.A. panelists had conflicts of interest or undisclosed financial interests in companies that, for instance, were developing Lyme vaccines and tests. Where does that investigation stand?**

The I.D.S.A. agreed to reconvene a guidelines writing panel of people, none of whom could have conflicts of interest. But what they also did was prohibit anybody who made more than, I think, \$10,000 from treating Lyme patients, to participate. So, that excluded all of the Lyme specialists; the community physicians who really know the disease the best.

**When you say that they're going to take another crack at the guidelines, does that mean that all 14 of the doctors on that panel are no longer on the IDSA board?**

Yes, they're not on the board. However, Dr. Gary Wormser, who chaired the panel, is still basically the go-to guy for Lyme disease at the IDSA. At the upcoming IDSA conference in the fall, there are, I think, only two panels on Lyme disease, and Dr. Wormser is presiding over them. So, he's still the authority. And anybody who's going to be on that panel—especially since they're not allowing the so-called Lyme literate physicians to participate—is going to be beholden to him and his point of view to some extent.

**Watching the film, I found myself thinking that the current presidential administration would probably want to see this movie before they put together a national health plan. Have you made any attempts to get President Obama to see it?**

Well, when we showed excerpts of the film on Capitol Hill in October, he had staffers who were present, and he wrote a letter to one of his constituents saying he knew about the film and he knew that Lyme disease was a big problem. And that he wanted to address that problem. We also have someone—a personal contact of Obama's who is hand-delivering the DVD to him.

**Why were you showing the film on Capitol Hill?**

It was a briefing organized for Congress by the National Capital Lyme & Tick-Borne Disease Association in Washington. This was right when the financial meltdown started and the room was still packed—standing room only. So there was a lot of interest and one Congressman Frank Wolf of Virginia actually personally delivered copies of the DVD to every member of the House and Senate Health Appropriations Committee. So, the film is definitely being used as a tool of awareness and hopefully to impact change.

**Do you find yourself getting any pushback from the insurance lobbyists or the doctors who were originally on the IDSA board?**

I think their strategy is to hang low and let this pass. So there hasn't been a lot of pushback. The official response from the IDSA is that the film is 'Long on Emotion and Short on Fact.' Now, that's not a surprising statement, but we also have a blog at the Under Our Skin [Web site](#) and in a recent post, we published transcripts of our interview with Dr. Willy Burgdorfer who discovered the Lyme bacteria. [The corkscrew-like pathogen is named *Borrelia burgdorferi* in his honor.] In the transcript, Burgdorfer says he believes that Lyme is a chronic infection, and he is very critical of the status quo, and of Lyme disease research conducted in the last 30 years. He calls it "a shameful affair."

**In your documentary, a journalist talks about how in the 1980s, the government permitted hospitals and research facilities to patent and profit from live organisms such as the Lyme pathogen. She explains that that led to a situation where researchers, instead of sharing their findings, tended to each hold onto their little piece of the puzzle, which made it difficult to put the big picture together. Is this still a problem in the field of Lyme research?**

Absolutely. I think it's the beginning of the problem. The deregulation of medicine happened under Reagan, and ironically,

Reagan died of Alzheimer's. I think he was an avid hunter, and you wonder if there's any connection there.

**You indicate in the film that if tests for Lyme disease were more accurate, the number of confirmed cases could be much larger than the number of confirmed HIV cases in America.**

The Center for Disease Control admits that their reporting is likely off from six to twelve fold, and that would make it over 300,000 [cases of Lyme] a year. I think, HIV is around 30,000 diagnoses a year. So, it doesn't even compare. Granted, everybody's who diagnosed with Lyme disease does not go on to develop serious chronic illness, especially if it's caught early. But what's happening is people are not being diagnosed early because doctors don't know what to look for because the tests are not accurate, and because there's no insurance code for chronic Lyme. On top of that, doctors don't want to treat chronic Lyme disease because it's just too much trouble. They risk losing their licenses.

**You follow a couple of doctors who come under fire for treating serious Lyme cases. One doctor loses his license to practice for a year and then is forced into bankruptcy when a health insurance provider sues him. And then there's the case of Dr. Charles Jones, the pediatric Lyme specialist with patients all over the world. What was remarkable to me was how many parents of children he successfully treated showed up to support and defend him at the hearing.**

He's still being dragged through the court. Years later, if it weren't for his dedicated patients who are helping with his legal fund, there's no way he could continue the fight. He's 80 years old and he's so committed. And here's something eye opening. *Forbes* magazine published an article about year ago that was critical of these Lyme-treating physicians, and the writer uses Dr. Jones as an example. He basically asserts that these physicians are quacks and out to get money. In the piece, he writes about Dr. Jones arriving at the hearing in a limousine. You know the only reason he arrived in a limousine was because he took his whole staff with him—it was a way that they could all fit in a single car. The guy works sometimes seven days a week. He has no life except for treating these kids and he's been smeared in the media. And if I didn't know better and hadn't done my own research then I would just believe that. So, this process has also made me question what I read. There's another story beyond the story. And that's the story we uncovered.

**It sounds like you are going to be immersed in this subject for a long time**

I've sort of become an accidental activist for the cause, but it's important to say that I didn't start out that way. I had no idea that the project was going to take on these dimensions. It was my curiosity and my compassion that brought me to this conclusion. It's the data, too—the hard data and the data of interviewing hundreds of people. And so, I feel a real commitment to those people. And I feel a real commitment to saving people's lives. So my work as a filmmaker in some ways is secondary to the issue of doing good in the world.

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