

VINEYARD GAZETTE

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Uneasiness Over Lyme Disease Spreads

By MIKE SECCOMBE

For close to two hours, in the new documentary *Under Our Skin*, the bad news about Lyme Disease was laid out before a capacity crowd at the Chilmark Community Center on Wednesday night. And it was very bad.

The good news came afterwards, and it was just a little bit good. But perhaps we should be grateful for anything which might lead to better treatment of this most difficult and mysterious of illnesses, which statistics suggest is probably more prevalent on the Vineyard than anywhere else in America, if not the world



Andy Abrahams Wilson, director of *Under Our Skin*.

Just a few days after the film had its premiere at New York's Tribeca film festival at the end of April, the major impediment to new treatments for Lyme, the Infectious Diseases Society of America (IDSA), agreed to reconsider its treatment guidelines.

The announcement came on May 1, the same day as Connecticut Attorney General Richard Blumenthal announced the results of an antitrust investigation he had initiated into the members of the IDSA board which wrote the 2006 guidelines relating to the disease.

The guidelines are commonly applied by insurance companies seeking to limit long-term antibiotic treatment or other medical care.

The investigation found significant conflicts of interest among the 14 doctors on the panel. Some held patents related to potential Lyme vaccines. Nine had relationships with insurance companies.



Panel discussion: from left, Dr. Daniel Cameron, Dr. Bernard Raxlen, Dr. Gerry Yukevich, film director Andy Wilson.

The legal examination concluded the panel had refused to accept conflicting information, even removing one member who dissented from their consensus opinion.

As a consequence IDSA, while conceding nothing amiss in its supposedly objective assessment of the disease and alternative medical treatments for it, agreed to set up a new panel, to be made up of some IDSA members, but also members of the lay public, some neutral physicians, a medical ethicist and, importantly, doctors from another group, the International Lyme and Associated Diseases Society, who hold contrary views.

Ultimately, it might lead to a rapprochement in one of the great debates in contemporary medicine, between those who think Lyme is a disease which is relatively easily treated and those who believe it is something far more insidious which can become chronic, needing long-term intensive treatment.

There was no doubt as to which side of the debate the documentary, two of the three doctors present to answer questions afterwards, and most of the audience stood.

They believe Lyme can be chronic. They believe, or at least see strong grounds to suspect, that Lyme is far more prevalent than the medical establishment and insurance companies would have people believe, and can be chronic, particularly if it is not caught early.

They challenge the establishment view, suggesting it can be passed on by sexual

activity, can pass from mother to child, can persist in a dormant state inside people for long periods, and can require long-term — meaning sometimes years of — treatment with antibiotics.

They also suspect it may be an overlooked cause of various medical complaints, and that undiagnosed Lyme might be implicated in other neurological conditions, including the cause of Alzheimer's disease, Parkinson's Disease, Lou Gehrig's disease and multiple sclerosis, maybe even some autism cases.

The documentary presents a powerful statement of all those suspicions. It traces the cases of several chronic Lyme sufferers, telling sometimes harrowing stories.

Like the mother who had four miscarriages; two of the fetuses tested positive for Lyme. She finally gave birth successfully, but her son also tested positive, although he has so far shown no problems.

Like the attractive young woman severely disabled by Lyme, who endures two years of antibiotic treatment, which at first seems to make her worse, before she recovers (a condition later explained as a Herxheimer reaction, which occurs when large quantities of toxins are released into the body as the Lyme bacteria die).



Large crowd turned out for screening of film Under Our Skin.

It presents example after example of people who have been misdiagnosed, and worse, suspected of having mental or emotional problems rather than a clinical illness, and who are forced to spend tens or hundreds of thousands of their own dollars because insurance companies will not pay up.

Indeed, the insurance companies come out looking nearly as insidious as the disease. There are case studies of doctors who treat for chronic Lyme, being dragged before medical boards — usually as a result of complaints by insurers — forced out of practice and sometimes sued.

On camera, sufferers confessed they sometimes wanted to die. The pains, the depression, the cognitive problems and the financial strains made life almost unendurable.

And after the film ended, one member of the audience added his own testimony. The man, a year after diagnosis with Lou Gehrig's Disease (a usually fatal, neurodegenerative disease), commended the film for pointing out that people not only suffered from the illness, but also from being "tortured" by the insurance companies' efforts to put good doctors out of business and then denying coverage to the sick.

The film got an endorsement, too, from another audience member, Dr. Diane Becker of Johns Hopkins University, author of the 2006 Health Report of Martha's Vineyard. She noted that the report found high rates of neurological problems and particularly marked rates of depression among Island residents.

She said Islanders should be "absolutely outraged" by the Lyme situation.

The three-member medical panel who fielded questions after the screening included two of the founders of ILADS, Dr. Daniel J. Cameron and Dr. Bernard D. Raxlen, as well as a local doctor, Dr. Gerry Yukevich.

All emphasized the need for more research into the disease, as well as four other tick borne diseases, often found in association — ehrlichiosis, babesiosis, tularemia and rocky mountain spotted fever.

As well as discussing the disease and his approach to it (he is a believer in treating it symptomatically, and said he frequently refers patients off-Island to doctors who treat chronic Lyme), Dr. Yukevich put in a strong pitch for culling deer, each of which he said carries an average of 12 to 20 ticks and possibly thousands of tick nymphs.

And each year, the Centers for Disease Control reports 20,000 new cases of Lyme. It is now the most common vector-borne (i.e., spread by a host such as a mosquito, or in this case, a tick) disease in America. But because of under-reporting and misdiagnosis, the figure could be 10 times higher.

The movie was truly frightening, not only because of its depiction of the sufferings of people with Lyme and associated diseases, but also for its depiction of the deep divisions among apparently respectable medical practitioners over what to do about it.

And it showed how far the science has yet to go in understanding it. The bacterium, it seems, possesses science fiction-like powers of metamorphosis from spirochete (spiral-like individual, to cystic state, to intracellular state, and, according to new research mentioned in the movie, apparently can aggregate behind bio-films which protect it from treatment and the body's immune system.

When, at the end of the screening of *Under Our Skin*, the director asked the audience to indicate whether they had ever had the disease, most people in the room raised a hand.

On the upside, if you are going to get Lyme, here is probably a better place than most to do it; at least the local doctors know what to look for.

Reader Feedback

Friday, August 15, 2008 1:07pm

From The Mountain...To The Sea- Thank you- Mary

- Mary , Boulder. CO

Friday, August 15, 2008 3:07pm

Great article! Thank you for being open to the possibility that perhaps the medically acceptable treatment protocol should no longer be considered acceptable for those of us with persistent symptomology. I was diagnosed 12 years ago and have been fighting the disease every day since. I've been waiting for the day that people wake up and realize that this is a far more serious bacterial infection than may in the medical community would care to acknowledge. Thanks again and good luck!

- Heather , Irvine CA

Friday, August 15, 2008 5:06pm

Having suffered with undiagnosed lymes for more than 6 months and then not properly treated for another 6 months, I know only too well the devastating effects of lyme. I also know how hard it is to find a "lyme literate" doc. Perhaps with this film, the insurance companies and the IDSA will start treating us instead of screwing us.

- Boots Tolsdorf , Nantucket, MA

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