



The Star-Ledger

Filmmaker finds untold suffering from Lyme disease

Tuesday, July 22, 2008

BY CAROL ANN CAMPBELL

Star-Ledger Staff

A provocative new documentary shows the controversy surrounding Lyme disease remains fierce three decades after doctors first diagnosed the illness in a small Connecticut town.

The latest entry into the long-running debate comes from a California filmmaker who explores patients diagnosed with the disease, some of them crippled, paralyzed with pain and neurologically impaired.

The documentary, "Under Our Skin," which will be screened tomorrow at the Montville Public Library, describes patients so ill they have been misdiagnosed with diseases such as amyotrophic lateral sclerosis and multiple sclerosis.

The film describes these patients as largely abandoned by a medical establishment that refuses to accept the existence of chronic Lyme disease.

Critics of that view, though, claim the movie distorts scientific evidence and further fuels misinformation surrounding the tick-borne illness, which is endemic in New Jersey.

"The overwhelming majority of people who have Lyme disease are cured with a conventional course of antibiotics," said Eugene Shapiro, a Yale University pediatrician and member of the Infectious Diseases Society.

Shapiro, who is quoted in the movie, said he was told the filmmaker wanted to make a balanced film.

"This is clearly not an unbiased movie," Shapiro said.

The filmmaker, Andy Abrahams Wilson, who grew up in Montclair, said he did not set out to create a polemical film, but that his investigation ultimately led to him side with the patients he believes are not getting treatment they need.

"I could not imagine that I tapped into thousands, hundreds of thousands, of people across the country who are not being helped and not being treated," he said.

There were 2,432 cases of Lyme disease reported in New Jersey in 2006, according to the U.S. Centers for Disease Control. Experts say the actual number is likely much higher.

The documentary has been shown at the Tribeca Film Festival in New York and is being shown at screenings around the country. (Information is at underskin.com.)

Wilson, in an interview, said he was stunned when a seriously ill friend diagnosed with ALS turned out to have Lyme. She improved with treatment. "I was just shocked that Lyme could do that and look like so many other illnesses," he said.

Wilson said the \$500,000 film was funded by two educational foundations with no ties to Lyme disease activists. He said the Turn the Corner Foundation, a Lyme disease organization, is helping to distribute the movie.

The documentary begins with the story of a woman so pained her fingers turn inward and she can barely walk. She is treated for two tick-borne illnesses, Lyme and Bartonella, and dramatically improves. The film also follows physicians brought up on charges by medical boards because they treated patients with lengthy courses of antibiotics, against standard guidelines.

The film follows a park ranger, a professional baseball player (misdiagnosed with Parkinson's disease) and a ballet dancer, among others, all treated for Lyme, a spiral-shaped bacteria. The film, heavy on personal stories, also includes the major players in this enduring medical debate.

One is Alan Macdonald, a Long Island pathologist who identified connections between Lyme and plaques in the brains of Alzheimer's patients. Another is Joseph Burrascano, an East Hampton, N.Y., doctor, recently retired from practice, who treated thousands of patients.

The naysayers are present, too.

Shapiro said he could not comment on the patients in the film, but he said Lyme disease is greatly over-diagnosed, and that at least four double-blind studies failed to show the value of long-term antibiotic treatment.

"When you say to someone that they do not have chronic Lyme disease, what they hear is that, 'You are not sick.' That is not what we are saying. ... We're saying the cause is not Lyme disease."

Carol Ann Campbell may be reached at ccampbell@starledger.com or (973) 392-4148.

©2008 Star Ledger

© 2008 NJ.com All Rights Reserved.