

Documentary tackles Lyme disease debate

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It wasn't long ago that filmmaker Andy Abrahams Wilson thought of Lyme disease as the whiner's disease.

"They get tired and sick and they complain a lot," was Wilson's view of those afflicted with the tick-borne illness, even when his twin sister fell ill.

Wilson took a second look at the disease after a good friend who'd been mistakenly diagnosed with multiple sclerosis and ALS, often referred to as Lou Gehrig's disease, turned out to have Lyme.

The neurodegenerative effects of Lyme were devastating, he said.

"She would walk into a supermarket and forget not only where she was but who she was," Wilson said. "It made me question my assumptions and the way I'd treated my twin sister."

The filmmaker took a closer look at Lyme, and the result is a documentary film, "Under Our Skin: An Infectious New Film About Microbes, Money & Medicine."

The 103-minute film, which debuted at the Tribeca Film Festival in New York this April, is being screened Tuesday, Wednesday and Thursday on Martha's Vineyard. The island, not coincidentally, has the highest incidence of Lyme disease in the state.

The film takes aim at delays in treatment for Lyme patients and the reluctance of the mainstream medical establishment to advocate long-term use of antibiotics for patients whose untreated Lyme has become deeply entrenched.

It particularly highlights the struggles of three Lyme patients — Jordan Fisher-Smith, a former park ranger in California, Mandy Hughes, a young bride in Florida, and Dana Walsh, a tour producer for the rock group U2 — to get treatment despite insurance claim rejections and dismissive doctors.

They experience chronic pain, bone-deep fatigue and cramping of the extremities that make them look like corpses going into rigor mortis. In addition to the three main subjects, the film also shows a baseball player mistakenly diagnosed with ALS, a young man who has to rely on a computer-generated voice to communicate and a young ballerina from Bedford, Mass., who can no longer walk.

Debate over treatment

Besides the Lyme patients themselves, the heroes of the film are "Lyme literate" doctors who are willing to treat patients with antibiotics beyond the two to three weeks recommended by the Infectious Diseases Society of America, who are clearly portrayed as the villains in "Under Our Skin."

"It's the largest vector-borne illness in the nation, and some people feel it's the fastest growing infectious disease in the country," said Wilson, a Sausalito filmmaker. But "physicians are not treating Lyme. They want to run the other way. How many people are not being diagnosed and not being treated at all?"

Two Cape Codders have screen time — Dr. Sam Donta of Falmouth, an infectious disease expert who treats patients long-term for Lyme disease, and entomologist David Simser, who is shown dragging a white sheet through woodlands to collect ticks for the Cape Cod Cooperative Extension Service.

While no Cape and Islands Lyme patients were included in the film, producer Kris Newby of Palo Alto, Calif., has a personal connection to Martha's Vineyard — and Lyme disease.

In the summer of 2002, she and her husband both got Lyme disease and another tick-borne infection, babesiosis, after a one-week vacation on the island.

Back in California, they had to go to about nine physicians before they found one who would even test them for Lyme disease. Newby had an "atypical rash" — it didn't look like the classic Lyme bull's eye — and a host of other debilitating symptoms.

"It would be like the worst symptoms of chronic fatigue, early dementia and arthritis all together," she said. Newby stopped working and the couple, parents of two boys, worried they might lose their home.

One doctor told Newby she had "Silicon Valley stress." Many doctors told her, "It can't be Lyme. It's a rare disease."

After nearly a year of being sick, she and her husband finally found a physician who agreed to put them on antibiotics for several months, not weeks. They both got better, although Newby said she has some lingering effects of the illness.

Newby and Wilson blame the IDSA for spreading the perception that Lyme is not only rare but easily treatable. In "Under Our Skin," Newby comes on camera to outline the links between IDSA members who wrote the conservative Lyme treatment guidelines and the insurers and pharmaceutical companies who paid them for services and research.

In a phone interview, she attributed the IDSA's narrow definition of Lyme to the rush several years ago to find a vaccine for the disease that was discovered in Lyme, Conn., in the 1980s. By using a strict definition of Lyme and less-than-sensitive tests for the illness, researchers made sure that people participating in the clinical trials really did have Lyme.

But even though the Lyme vaccine turned out to be problematic and was pulled off the market, the Lyme establishment is sticking to that narrow definition of the illness, Newby said.

It's left to clinicians like Donta on Cape Cod to try and help patients who complain of lingering effects of Lyme, including memory loss, problems with word retrieval, vertigo, loss of the ability to speak, severe joint pains, headaches and depression.

Increasing the suffering?

The "majority of these patients do get well," proving that antibiotics work, Donta said. But "it takes longer than a month or two."

It's up to individual doctors how long they want to prescribe antibiotics for, but state medical boards have taken action against physicians for what the boards consider overuse of antibiotics.

Donta was on the IDSA panel that published guidelines about Lyme disease in 2000, but he said he wouldn't sign them after a conservative definition of the disease was written in. And Donta said he wasn't invited to re-join the panel when it met again in 2005.

According to the IDSA, long-term treatment with antibiotics doesn't have any impact beyond a placebo effect and may contribute to the development of "superbugs" that cannot be treated with available drugs.

In a letter to the Cape Cod Times from the IDSA last year, Dr. Henry Masur wrote, "Far from improving the patient's quality of life, prolonged antibiotic therapy may actually increase the patient's suffering."

But 64-year-old Barbara Whittaker-Johns of Orleans said she "got better right away" after receiving antibiotic treatment from Dr. Bernard Raxlen, a physician practicing in New York City who is featured in "Under Our Skin."

Whittaker-Johns had to go on medical leave from her job as a Unitarian Universalist minister in Arlington after getting sick and suffering from nerve pain, shingles, stroke-like incidents and heart problems that caused her to faint while officiating at a wedding.

She ultimately lost her job but regained her health. "Physically I'm fine, and I'm grateful for that," Whittaker-Johns said.

"It's not a death illness," said Raxlen when interviewed by phone. "It's a death of quality of life illness."

Lyme patient Joanne Creel of Yarmouthport watched "Under Our Skin" after a friend gave her a copy of the DVD.

A former marathon runner and a social worker who works part-time counseling fellow Lyme patients, Creel wishes every physician would view the film.

"I cried when I first saw it," she said. "Finally, somebody has put a voice and affirmed how serious this disease is."

Lyme cases declining

The Cape and Islands have the highest incidence of Lyme disease in the state, although the number of cases has dropped, according to the latest figures provided by the state Department of Public Health.

In 2006, the last year for which the DPH has figures, the incidence of Lyme disease per 100,000 residents was 293.6 for Dukes County, which covers Martha's Vineyard, 241.6 for Nantucket County,

and 79.2 for Barnstable County on Cape Cod.

The number of local cases dropped from 2005 to 2006, falling from 240 to 176 in Barnstable County; 90 to 44 in Dukes County and 32 to 23 on Nantucket.

Elsewhere in the state, Lyme disease rates went up, and the total number of cases in Massachusetts was down only three to 2,446 in 2006.