

# Bedford teen in fight for Lyme disease funds

By Christine McConville | Wednesday, September 24, 2008 | <http://www.bostonherald.com> | Business & Markets

After losing a third of her life to Lyme disease, Marlena Connors is eager to catch up with her peers.

She's working to get her high school diploma and telling people about the six-year health odyssey that began with a red welt the diameter of a grapefruit on her back.

Diagnosed at age 13 with late-stage Lyme disease, Marlena was so sick that she had to leave school and quit ballet. Now 18, she's mostly healthy.

Marlena and her family, who live in Bedford, play a significant role in the documentary, "Under Our Skin." It aims to raise awareness of a disease that some say is woefully misdiagnosed.

The National Capital Lyme and Tick-Borne Disease Association will show portions of the film on Capitol Hill during a congressional hearing today on the disease. The national advocacy group and patents - including the Connors - will ask Congress to take another look at Lyme.



Photo by Mark Garfinkel

It has been more than 15 years since Congress last examined the disease, and members of the national committee hope that a new review will lead to better diagnostic tools, more research funding, and a stronger push for a cure.

Activists also want to have late-stage Lyme disease reclassified as a chronic illness, a move that would require health-insurance companies to pay for long-term antibiotic therapy. So far, the effort hasn't been successful; some medical organizations deny that it is a chronic disease, while others say such treatment could be harmful.

Lyme disease is transmitted to humans from bacteria-infested blacklegged ticks. It is named after the Connecticut town where there was a well-known outbreak in 1975.

Symptoms include fever, headache, fatigue and skin rashes. If left untreated, the infection can spread to joints, the heart and nervous system.

According to the Centers for Disease Control and Prevention, some 20,000 people acquire the disease each year, and most are successfully treated with a few weeks of antibiotics.

Marlena Connors' mother Sandra disputes that. She said yesterday that the disease has reached epidemic levels, but because it is so frequently misdiagnosed and under-reported, the government isn't aware of how prevalent it is.

Even as Marlena's rash spread and her temperature soared, the Connors' doctor declined to test the girl for Lyme disease.

"He said the test had too many false positives," she said.

Six months later, after Marlena's knees and ankles had swollen, another physician determined that she had late-stage Lyme disease.

As her parents searched for effective treatment, Marlena found her body frequently shut down, and she became increasingly isolated.

It was at the world premier of "Under Our Skin," in New York City, that she met - for the first time - other Lyme disease sufferers.

"I know it sounds strange," she said, "but that was awesome."

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