

Lyme disease patients face an uphill battle

By **Ira T. Weiss**
Staff Reporter

DUTCHESS COUNTY—Lyme disease and other tick-borne related diseases pose a serious health threat to many residents in the northeastern United States. Dutchess County in particular has the greatest number of recorded cases. According to Andrew Evans of the Dutchess County Health Department, there were 1,700 new confirmed cases in 2002, up from 1,006 in 2001. Living with Lyme disease can be a painful, disorienting experience, and it can be life threatening if the patient is unable to receive treatment.

The Centers for Disease Control and Prevention (CDC) Web site states that only one in 10 cases gets reported.

According to the American Lyme Disease Foundation (ALDF) only 70-80% of all people bitten by a tick with Lyme disease actually see the characteristic bulls-eye rash at the tick bite site. The Lyme Disease Association says that it is even lower, only 50%.

The ALDF states that the early stages of Lyme can be masked by flu-like symptoms such as chills, mild-fever, headache, fatigue, joint pain or swollen lymph glands. If these symptoms are bypassed, later stages of the disease may occur weeks, months or years later. Chronic Lyme disease may then result.

Jill Auerbach, coordinator of the Hudson Valley Committee for Lyme Disease Patient Advocacy, said co-infections are not only prevalent but also make diagnosing and fighting the infections that much more difficult. Auerbach was diagnosed with Lyme last year, but only after a two-stage testing approach was used.

According to the "Diagnostic Hints and Treatment Guidelines for Lyme and Other Tick Borne Illnesses," written by Joseph J. Burrascano Jr., M.D., "Lyme Disease is not simply an infection with *Borrelia burgdorferi* (Lyme Borreliosis), but a complex illness potentially complicated by multiple tick-borne co-infections."

A study that was conducted in

1998 jointly by the Institute of Ecosystem Studies in Millbrook and the Department of Ecology and Evolutionary Biology of the University of Connecticut showed that 53 out of 188 ticks (28%) had both Lyme Borreliosis and Ehrlichiosis. And this is only one combination of pathogens that may be transmitted from one tick bite.

New York State Assemblyman Joel Miller has been for many years a strong advocate for defending the rights of patients and doctors who have and treat Lyme.

"There is no single test at this point that is accurate enough to detect if you have chronic Lyme," said Miller.

According to Auerbach, Lyme diseases are difficult to detect and to treat and that many doctors are using a one recipe "cookbook" to treat patients and not looking at each individual case.

"What works for one person may not work for another. Immune systems are different," said Auerbach.

Maureen Orr of Red Hook said it took more than a year to be correctly diagnosed, and due to the inability of local doctors to treat her illness, she has resorted to travelling to Westchester County to see a Lyme specialist. In some cases, doctors were not knowledgeable enough to provide treatment. Orr's initial tests for Lyme disease failed to find any antibodies. Her immune system wasn't detecting the invading organism.

"We have rheumatologists, internists and infectious disease specialists who are refusing to treat these patients stating that they have Fibromyalgia, Chronic Fatigue Syndrome or an auto-immune disease," said Miller.

Burrascano's guidelines say that the longer the patient has the disease, the greater the suppression of the patient's immune system.

According to Miller, many physicians refuse to treat patients beyond the present CDC prescribed treatment of 3-4 weeks with doxycycline or amoxicillin after initial diagnosis due to the

fear that the New York State Office of Professional Medical Conduct (OPMC) may investigate.

One physician told Orr, "I think a lot of my patients are struggling with Lyme and I want to help them and I want to help you, but I don't want to lose my license."

"It is a very expensive treatment," said Miller. "And I believe that the expense involved is what triggered the complaints; most of which have come from the insurance companies."

Orr's intravenous antibiotics cost \$1,650 per week.

Miller said that the OPMC is unfairly singling out and investigating doctors who are using long-term antibiotic treatments for the treatment of Lyme disease and that current regulations do not allow doctors due process rights to protect and defend themselves.

The proposed OPMC reform bill, named for Assemblyman Richard Gottfried, is before the New York State Legislature to reform the OPMC to allow physicians basic civil rights.

Also before the Legislature is the proposed Mayersohn Bill, named for Assemblywoman Nettie Mayersohn. This bill specifically provides that a physician's license couldn't be subject to professional misconduct proceedings for prescribing long-term antibiotic treatment for patients with Lyme or other related tick-borne diseases.

"We want to stop the witch hunts," said Miller.

Anyone interested in supporting these bills is urged to contact their local state legislators or contact Senator Joseph Bruno, Majority Leader, Room 909 LOB, Albany 12247, (518) 455-3191.

For more information regarding the Gottfried and Mayersohn Bills, and/or Lyme disease advocacy, go to the Voices of Lyme Web site at, <http://www.lymeinfo.net>.

"Medicine is still an art and not everything falls into a neat package," said Miller. "This is clearly an unsettled scientific issue."