

Lyme disease report spurs patients' rights protests

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A new report on diagnosis and treatment of Lyme disease has divided the medical community and outraged patients' advocates, who claim the new guidelines will further endanger victims of the tick-borne disease.

And now, Attorney General Richard Blumenthal is investigating whether the Infectious Diseases Society of America discounted competing views when it published its controversial new guidelines in the November issue of *Clinical Infectious Diseases*.

Among the report's most controversial points is its finding that the vast majority of Lyme disease cases can be treated in less a month, an assertion that has infuriated activists who believe the new guidelines will mislead physicians, restrict treatment options for patients and allow insurance companies to refuse compensation for treatment.

Sandy Berenbaum is a Southbury resident who struggled with the disease for six years before it was finally diagnosed in 1990. A social worker who runs a counseling clinic in Brewster, N.Y., Berenbaum has seen many children ravaged by the disease over her years of practice.

One boy suddenly turned psychotic and had to drop out of school. Another one couldn't walk or speak and became so sensitive to noise that he had to wear noise suppressors on his ears. In both cases, she said, the patients ultimately recovered after years of Lyme treatment.

"These guidelines take away the ability of doctors to use their clinical judgment," Berenbaum said. "They are extremely restrictive and they are essentially claiming that anything beyond 30 days is not an active, persistent infection and should not be treated."

On Oct. 30, Berenbaum was one of about 300 people from 16 states at a rally at Westchester Medical Center in Valhalla, N.Y., which employs three members of the IDSA committee that issued the report, including lead author, Dr. Gary Wormser. Also in attendance were Maggie Shaw, a registered nurse from Newtown who co-founded the Newtown Lyme Disease Task Force, and Colleen Collins, a Wolcott resident who became a patient activist after her four children contracted the disease in 2003.

Both Shaw and Collins have suffered from Lyme disease and say doctors have repeatedly misdiagnosed their symptoms. Shaw said her son Ryan, now 18, suffered from the disease between the ages of 4 and 10, during which time his symptoms included severe anxiety, arthritis in every joint of his body, intense rages and partial facial paralysis. Her daughter Taylor, now 15, developed a rash on her face when she was 12, but her doctor told her to consult a dermatologist. When Taylor developed six more rashes the next day, Shaw knew the problem was more severe than initially feared.

Her other son, Grant, 10, suffered hallucinations until he began to regularly take antibiotics.

"Almost every drug we used, the IDSA guidelines say we shouldn't take," Shaw said.

Collins's problems began in May 2003, when her daughter Kaelee, now 10, was bitten by two ticks and became infected. But even as Kaelee suffered through seizures, headaches and severe nausea, none of the doctors she consulted could tell her what's wrong. Her three siblings also contracted Lyme disease and suffered symptoms ranging from leg paralysis, intense blinking, burning sensations and dilated pupils.

Collins and Shaw said their children's conditions only started improving after they consulted Dr. Charles Ray Jones, a New Haven-based Lyme disease specialist. Most other doctors, Shaw said, are misinformed about the disease and will become even more confused because of the IDSA guidelines, which are treated as more or less sacrosanct by the Centers for Disease Control, which links to the guidelines from its Web site.

"These guidelines are keeping doctors ignorant of the disease," Collins said.

Dr. Eugene Shapiro, one of the 14 authors of the IDSA report, said that while it's possible for people who previously suffered from Lyme disease to develop paralysis or other symptoms after their disease was treated, that doesn't mean that the new symptoms are necessarily related to Lyme disease. The report, he said, is based on the best scientific evidence, which he said argues against use of antibiotics.

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"There is no evidence of benefits from prolonged courses of antibiotics and substantial evidence of multiple risks to patients and society," said Shapiro, a professor at Yale University School of Medicine Department of Pediatrics. "We had numerous reports of people dying from complications, including cases of red blood cells breaking apart and problems with gall bladders.

"The key is to base your approach on scientific evidence, not anecdotes," he said. "If someone says they have Lyme disease, what evidence do they have that it's really Lyme?"

Dr. Raphael Stricker, a San Francisco-based Lyme disease specialist, said such a response ignores the pattern of symptoms exhibited by victims of Lyme disease months and years after the initial diagnosis. Stricker serves as president of the International Lyme and Associated Disease Society, an organization of about 300 Lyme experts that has its own guidelines for treating the disease. Shortly after the IDSA report was published, Stricker wrote a letter to Clinical Infectious Diseases calling for a retraction.

"They took ILADS guidelines and took out everything we recommended," Stricker said. "This is a clear attack on what physicians are doing and it's extremely restrictive.

"These guidelines will have a chilling effect on physicians, who will now be unwilling to treat diseases because otherwise they will have to explain to medical boards why they aren't following the IDSA recommendations," he continued.

The biggest beneficiaries of the new report, he said, are insurance companies, who can now use the guidelines to justify not compensating victims for treatment beyond the 30-day period.

Blumenthal agreed. Last month, he launched an investigation to uncover whether IDSA excluded dissenting opinions when putting the report together. While he said there is no evidence that any laws have been violated, he pointed out that the panel "seemed to have been limited to physicians with one point of view." As a result, consumers may find that their options for receiving treatment are severely restricted, he said.

"Whatever the physician and the patient decide is appropriate must be covered," Blumenthal said. "These guidelines potentially restrict the treatment and diagnostic measures and, thereby, enable insurance companies to restrict their coverage."

In Connecticut, where Lyme disease was first recognized, there were 1,810 reported cases of Lyme disease in 2005, a 34 percent increase from the previous year, according to CDC. Only New York, Pennsylvania, New Jersey and Massachusetts had more reported cases.