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From the Baltimore Sun

Missing the mark

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Lyme patients - many of them afflicted with debilitating ailments that began with the bite of a tiny tick - have traveled from Maryland and a dozen other states to a medical center in Valhalla, N.Y., where today they will demand that the Infectious Diseases Society of America retract medical treatment guidelines it released last month. Lyme disease sufferers experience headaches, fatigue, chills, fever and, in advanced cases, heart and nervous system problems. The last thing they needed was to have their pains burdened additionally by a segment of the medical community that by recommending against long-term antibiotic use essentially threatens to reduce the quality of care they receive.

Maryland averages about 17 reported cases of Lyme disease per 1,000 residents, ranking it seventh in the country. Most of the cases can be found on the Eastern Shore, where not only are infected ticks plentiful, but Lyme disease education is promoted aggressively by volunteer health-service activists who also happen to be Lyme patients.

The illness is easily misdiagnosed and frequently undertreated. Lyme patients have no shortage of horror stories about how their early symptoms were casually dismissed as arthritis, a lack of sleep and proper diet or, even worse, an emotional disorder, before they found a sympathetic physician who finally pinpointed the problem and prescribed antibiotics. In too many cases, the prognosis came late and the patient had to accept living with the disease.

The most contentious piece of the new IDSA guidelines is a claim that long-term use of antibiotics is not a remedy and that they should not be prescribed beyond initial preventive doses. Lyme patients and their doctors are understandably shocked by this assertion. Their own experiences tell them differently. And though adherence to the guidelines is voluntary, the implications are that insurance companies and HMOs will refuse to pay for further antibiotic treatment and that doctors, even against their better judgment, will stop prescribing for fear of being brought up before medical boards.

Maryland's Lyme-literate physicians and their patients would have had some protection against the IDSA guidelines had a prescient bill addressing this issue made it through the state legislature in 2005. By the time the bill came up for a final vote, it was so watered down in favor of the insurance industry that even its original backers sanctioned its demise.

On the matter of helping Lyme patients cope with the disease, the IDSA - like the 2005 legislature - missed the mark by a mile.

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