

# Re: Battle lines have been drawn over new clinical guidelines

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*Source:* <http://sci.tech-archive.net/Archive/sci.med.diseases.lyme/2006-11/msg00290.html>

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- *From:* "no longer pissed off" <[mockingbirdstl@xxxxxxx](mailto:mockingbirdstl@xxxxxxx)>
  - *Date:* 9 Nov 2006 22:06:30 -0800
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here's the DL on the "mass murderer" epithet. on june 11, 2006, I posted this and later the same day removed it at 3rd mans coaxing. suddenly, on november 6, 2006, just in time to support the wormser healthday article, the same post re-appears at a site called 'gatago.com'.

in other words, I removed the offending post the same day it was posted back in june, and some sneaky bastard took that and reposted it under my email on november 6.

the author of the above article is being notified, and efforts are being made electronically and otherwise to track down the individual{s} responsible for this chicanery.

Mr. Erickson loves Peenies wrote:

THURSDAY, Nov. 9 (HealthDay News) — Battle lines have been drawn over new clinical guidelines on spotting and treating Lyme disease.

Depending on whom you talk to, the new recommendations from the Infectious Disease Society of America are the "best that science has to offer" on the illness, or a medical "travesty" that will lead to the suffering and even death of those affected by the tick-borne disease.

The former view is held by Dr. Gary Wormser, the infectious disease specialist who chaired the panel that drew up the new guidelines, which are published in the November issue of Clinical Infectious Diseases.

Specifically, the updated IDSA recommendations — the first since 2001 — state that "95 percent of cases of Lyme disease are cured with 10–28 days of oral antibiotics."

They also state that there is currently no credible scientific evidence that infection with *Borrelia burgdorferi* — the tick-bone bacteria that

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cause the painful illness — extends much past this period in patients who are treated soon after diagnosis.

That runs counter to the notion, held by many, that longer-term, "chronic" Lyme disease exists as a clinical condition.

The guidelines also strongly object to the use of antibiotics in patients beyond those 30 days, since long-term antibiotic treatment comes with its own medical risks.

While there's no rule that physicians must follow IDSA recommendations when treating Lyme disease, insurance companies often base their treatment coverage on these types of guidelines. State medical boards might also consult the recommendations when reviewing alleged malpractice cases.

All this means that "patients are now contacting us in droves all the time about their inability to get treatment," said Pat Smith, president of the New Jersey-based Lyme Disease Association, which represents 24 patient-advocacy groups across the United States.

Smith and other patient advocates are vociferous in their opposition to the IDSA guidelines. They argue that the recommendations are based on an incomplete, biased review of the science and fly in the face of observed clinical outcomes.

"I will tell you that from my experiences with tens of thousands of people from across the country, these chronic patients are helped by antibiotics," said Smith, who has two daughters affected by Lyme disease. "If they are helped by antibiotics, they should be allowed to have them."

Instead, she said, insurance companies are citing the recommendations as they cut off many patients' access to treatment.

Dr. Raphael Stricker is a San Francisco Lyme disease specialist and president of the International Lyme and Associated Diseases Society (ILADS) — the largest medical organization devoted to Lyme illnesses. His group recently sent a letter to Clinical Infectious Diseases, asking that the journal retract the IDSA guidelines.

Stricker said he routinely ignores the guidelines in his own practice.

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But he added that he is able to do so because California has laws in place that protect physicians "who want to treat according to their own best judgment." Most states do not have such laws.

"So, if I were practicing in another state that did not have this protection, I would be very scared right now because of the IDSA guidelines — I might be brought up before the board," Stricker said. "I think the guidelines are definitely having a chilling effect in the rest of the country."

Smith said she's also heard "from several people whose insurance companies have cut them off [from treatment] without anything but pointing to the new guidelines."

But Wormser said his group based the new recommendations on solid evidence.

"We looked at almost all the science that we could find on the subject," said Wormser, who is chief of infectious disease at New York Medical College, in Valhalla, N.Y. "In the guidelines, we actually cite over 400 studies."

He said the evidence from all this data was clear: There is no good evidence that *Borrelia* bacterial infection persists past the first few weeks of treatment. That means that the risk to patients of long-term antibiotic therapy is unwarranted.

He also pointed to studies that show that people with a prior Lyme infection are no more likely than others to develop long-term problems.

Wormser stressed that he and his colleagues do not deny that the symptoms patients complain of are real. However, instead of labeling these symptoms "chronic Lyme disease," Wormser prefers "post-Lyme syndrome." The distinction is an important one — similar language has long been used to describe individuals who were once stricken with polio and who go on to develop a constellation of long-term symptoms called "post-polio syndrome," for example.

Wormser said intensive research is needed to determine what causes debilitating, long-term symptoms in patients with no trace of *Borrelia* in their cells. Right now, he said, doctors don't even agree on what symptoms characterize long-term illness. "How do you know when a person has it? What definition is there for it?"

According to Wormser, long-term sufferers complain of a wide variety of symptoms, many of which can be caused by other ailments.

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"So, if you don't rely on some other test method — just on your own [physician] intuition — you can't possibly diagnose it correctly," he said.

Stricker takes another view, however.

"I have over 900 Lyme patients, and there is actually a lot of consistency in the type of symptoms patients have," he said. "So, my response to Dr. Wormser is that when you have a lot of clinical experience treating patients, you see patterns and you understand that things are treatable."

Stricker also contends that the IDSA panel did not, as Wormser claims, survey "all" the literature on Lyme disease. He said that, since the disease first emerged 30 years ago, more than 18,000 papers have been published on the illness. "He just looked at all the studies that he considered significant — that's about 2 percent of the literature," Stricker said.

The IDSA guidelines do include one important disclaimer: A note that the recommendations "are not intended to supplant physician judgment with respect to particular patients in special clinical situations."

But critics called the disclaimer little more than window-dressing.

"That's not the way the guidelines are going to be interpreted," said Tom Forschner, executive director of the Lyme Disease Foundation, another patient-advocacy group. "Docs and insurance companies are going to look at [certain treatments] and say, 'Well, that violates the IDSA guidelines, therefore you are not going to be reimbursed or treated.' And that's where patients will suffer."

A Web search on Wormser quickly turns up scathing epithets from detractors who call him a "mass murderer" and "Dr. Death." Wormser said he's been puzzled by the animosity the guidelines have generated.

"We're not trying to do anything evil, we're actually very concerned about these patients' symptoms," he said. "We really encourage people to do further studies to find out what's causing this."

But Stricker believes the IDSA panel ignored the collected evidence and has now boxed itself into a kind of intellectual corner.

"At this point, it's really just politics," he said. "Politicians don't want to admit that they are wrong, and these guys don't want to admit that they are wrong, either