

Lyme treatment at center of debate

Source: <http://sci.tech-archive.net/Archive/sci.med.diseases.lyme/2008-06/msg00124.html>

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 - *Date:* Fri, 13 Jun 2008 21:32:44 -0700 (PDT)
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Lyme treatment at center of debate

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June 12, 2008 6:00 AM

"The debate about the existence of chronic Lyme that is Lyme-type symptoms that have lasted longer than six months has been around for quite some time," says Dr. Don McNeel, of Hampton's Seacoast Lyme Center.

It's a hot topic, with camps in the medical field at odds with each another and those dealing with devastating health issues feeling caught in the middle.

Lyme disease, the tick-borne illness, is difficult to diagnose. False-negative test results occur frequently, a fact on which both sides in the debate agree. It's the treatment that lies at the center of the battle. The usual course is a two- to four-week regimen of antibiotics. But some familiar with the issue say that's not always enough. Chronic cases exist. Symptoms may subside after treatment, appear to vanish then re-emerge with a vengeance, often with more symptoms and worsening health.

The doctor you choose after the first treatment fails can determine whether you find support or a revolving door of specialists and no relief, says Marguerite Mathews.

For a number of years, Mathews, the co-director of Pontine Movement Theatre in Portsmouth, has lived a hellish health existence, one many with chronic Lyme experience, she adds. It started with a round of doctors, a number of misdiagnoses and in some cases being told it was in her head.

Many patients will find themselves bouncing between primary-care providers and a variety of specialists from the fields of infectious disease, neurology, rheumatology, orthopedics, pain management, even psychiatry, says McNeel.

"After all the tests come back normal ...; they end up being referred to the psychiatrist for 'somatization disorder,' 'anxiety' or

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'depression,'" he says. "If they're lucky, they'll eventually find their way to one of the organizations seated in the outsider camp, groups such as the Lyme Disease Association or International Lyme and Associated Disease Society (ILADS) those that believe it can take more than two weeks of antibiotic treatment."

The more traditional medical camp which includes the Infectious Diseases Society of America, the U.S. Centers for Disease Control (CDC) and National Institutes of Health tends to refer to the continued occurrence of symptoms as "post-Lyme syndrome," says McNeel. "Their idea is that the bacterium is all dead after a short two-week antibiotic course but a residual effect occurs with the immune system. The ILADS position is that the bacterium is stealthy and hides from the immune system. Therefore, you have to tailor the treatment for the individual patient. A set, two-to-four-week, cookie-cutter approach treatment may not work with everyone."

The CDC's adherence to the short-term treatment allows insurance companies to refuse payment for treatments outside that regimen, says Lorraine Johnson, in her article "Lyme Disease: Two Standards of Care," a reference McNeel sites. Johnson is a lawyer who is also the executive director of the California Lyme Disease Association. "Prolonged treatment is not experimental," Johnson says. "It is how other persistent or relapsing infections in general have been treated for years (e.g. tuberculosis, leprosy, bone infections, etc). Most of medicine is practiced in the grey zone of uncertainty where the medical evidence is not clear in these circumstances we have to rely on the clinical judgment of the physician and this clinical judgment should not be constrained by treatment guidelines (like those of the IDSA) that preclude treatment options. "

Mathews' symptoms started with what appeared to be a flu, with four days of high fever. Then, in late spring, she says she began experiencing "incredible muscle pain in my shoulders and neck...; It would wake me up. Nothing relieved the pain."

First came a flu diagnosis; then one for muscle injury and a prescription for pain.

"The next day I woke up and my face was paralyzed. I knew people that had Bell's palsy ...; I knew it was a possibility, it was not stroke."

Mathews actually tried to go on with a performance booking, but ended up at the hospital. She was diagnosed with Lyme disease and put on a "strong dose of antibiotics and anti-viral medication, 'cause ticks can carry both (bacteria and viruses)."

Johnson's article explains the difficulties in making a proper diagnosis stem from the lack of sufficiently sensitive and reliable biological markers of the disease. She adds that the most beneficial

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treatment for persistent Lyme disease has simply not been established.

"No single antibiotic or combination of antibiotics appears to be capable of completely eradicating the infection, and treatment failures or relapses are reported with all current regimens, although they are less common with early aggressive treatment," she writes.

In addition, she says, neither side has the scientific evidence to fully support its viewpoint. "Outcomes research is limited and conflicting," she says. "The point, of course, is that the science underlying both the short-term and the longer-term treatment options is equally uncertain."

When attempting to manage her care, Mathews found herself in no-man's land. She was treated and told "you're better now."

"That was August. ...; then in October I started feeling bad again, twitch things in the face, nerve pain in ear, loud ringing, muscles in pain. I went back to the doctor," she says. "I was also having vertigo, disorienting feelings."

A number of specialists followed. The frustration continued. Mathews was told there was nothing more they could do for her. At times she was told "it's in your head."

Frustrated, she started researching the subject and found support groups and for the first time conversation regarding the controversy.

"I saw the symptoms called 'active Lyme,' and another point of view...; that says Lyme is extremely complex, that it has different ways of hiding in the system ...; and like syphilis and TB, it requires long-term treatment to kill it off. It was frightening.

"Your symptoms are worse and you're in the middle of a political controversy. ...; So, when someone says, 'we have a way to treat you ...; to help you feel better,' I'm going with it."

Mathews reached out to Know Lyme in New Hampshire, and other support groups.

Until meeting in person, no one would discuss a particular physician for fear the doctor would be shut down by the medical board. "You try not to draw attention to doctors or the alternative treatment," she says.

Today, she's being treated with a combination of antibacterial medications. She expects to be on them for 12 to 24 months.

"My symptoms are enormously better. My face stopped twitching, the joint pain has decreased. I still have symptoms but they're much

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milder," she says.

And, she's one of the lucky ones, she adds. She's met others in wheelchairs, or losing their sight from chronic Lyme. "It feels so unfair. Boom, you're in the middle of this crazy stuff. I also wonder why the CDC is so opposed to this treatment. They have no problem treating TB or malaria with long-term, antibiotic treatment; even teens with acne. But with this, they're denying it."

Seacoast resident Christy Cloutier Holmes has dealt with the illness for three years. Today it's in remission. Given her experience with chronic Lyme, she believes it can hit again at any time. "It already has," she says. "I've had my ups and downs."

Her initial diagnosis was depression. But the aches, pain, and exhaustion kept her digging. And she personally never felt she was depressed. Eventually, she was diagnosed with chronic Lyme and sought treatment from a local naturopath.

An average monthly treatment ran her \$150, much cheaper than some drug regimens, but a lot on a working mom's salary. In the end, the larger cost was time lost at work. The symptoms were so severe she lost an entire summer of work. Today, she's careful, keeps watch on her health and works to keep her immune system strong. But she knows if her symptoms go into remission, it doesn't mean she's cured.

As the debate rages on, patients remain caught in the middle, unclear where to turn, not sure what to do.

"The danger is in trying to blame all of life's issues on a single infection," says McNeel. Life is complex and multifactorial. Neither side had the complete answer. Yet, the debate itself compromises patient care."

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