

Inaccurate Information About Lyme Disease on the Internet

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Objective: Patients and families searching the Internet about Lyme disease may find conflicting information. Our purpose was to review the accuracy of information on Lyme disease easily available on the Internet.

Methods: We used 15 search engines to find general information about Lyme disease. We found 251 Lyme disease websites, which we reviewed. Of these 251 websites, 19 gave general Lyme disease information and were analyzed. We evaluated the accuracy of information concerning 8 Lyme disease topics.

Results: Ten of the 19 websites gave accurate information and 9 of the 19 websites provided inaccurate information. There were 8 websites with the word "Lyme" in the domain name, and 7 of the 8 sites gave inaccurate information. There were 2 ".gov" websites, and both gave accurate information.

Conclusions: Patients and families searching the Internet for medical information about Lyme disease may encounter inaccurate information.

Key Words: Lyme disease, the Web, inaccurate information

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The Internet is a frequently used source of medical information for patients and families.¹ This information usually is accepted as accurate,² and families use Internet research for participation with their physicians in medical decision-making.^{1,3,4} In the past 5 years, we have observed that the majority of families managed in our pediatric Lyme disease clinic have researched Lyme disease on the Internet before their visit. Some families presented to our clinic to discuss information found on the Internet because it contradicted what they had been told by their physicians. As an example, we have seen new mothers who were being treated for Lyme disease and would not breast-feed because they had read on the Internet that breast-feeding could pass Lyme disease to their infants. Lyme disease has never been passed

in breast milk to an infant.⁵ The following study reviews the accuracy of Lyme disease information readily available on the Internet.

METHODS

Search Strategy

The program Copernic Agent Personal version 6.0 (Copernic Technologies, Inc.) was purchased to identify websites containing information regarding Lyme disease. This program queried the following 15 search engines simultaneously: AltaVista; AOL.com Search; CompuServe; EuroSeek; FAST Search; Google; HotBot; LookSmart; Lycos; MSN Web Search; Netscape Netcenter; Open Directory Project; Teoma; WiseNut and Yahoo. Up to 20 results were returned for each search engine accessed. Searches were performed using the following 5 phrases: *Lyme*; *Lyme disease*; *chronic Lyme*; *chronic Lyme disease*; and *Lyme arthritis*.

Compiling results from all 5 searches and removing duplicates yielded a list of 251 sites. All sites were reviewed. Websites that contained only anecdotal stories or personal accounts of Lyme disease were excluded as were websites that contained only hyperlinks to other sites without content of their own. Sites not written in English also were excluded. Furthermore only sites that contained multiple pages and/or sections giving general information about Lyme disease were included for study. Nineteen websites met these criteria and were studied.

Evaluation

The accuracy of the information with respect to 8 Lyme disease topics^{5–29} was evaluated for the 19 websites. The topics were chosen because they are of general interest to lay people and physicians. The generally accepted (included in position statements by the Academy of Pediatrics,⁵ the College of Rheumatology⁶ and the Infectious Disease Society of America⁷) and evidence-based information for these 8 topics is as follows.

What Should Be Done for a Tick Bite? The general risk of developing Lyme disease after a deer tick bite is 1–3% if the tick bite occurred in a Lyme disease endemic area. To transmit Lyme disease, the risk is highest for ticks that are attached for >24 hours. Antibiotic prophylaxis following a tick bite is not routinely recommended because if Lyme

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disease develops it can be easily treated. Testing the tick by polymerase chain reaction (PCR), to see whether it is carrying *Borrelia burgdorferi*, is not recommended because it is expensive and false-positive or false-negative results occur. However, if prophylaxis is prescribed, possible regimens include amoxicillin (250 mg 3 times daily for 10 days) or doxycycline (a single dose of 200 mg).^{5,7-12}

How is Lyme Disease Diagnosed? The diagnosis of Lyme disease is based on objective findings. These objective findings include the characteristic erythema migrans rash, a circular, expanding rash with or without central clearing (≥ 5 cm in diameter) beginning within 30 days of deer tick exposure (in a Lyme disease-endemic area). Positive serology for *B. burgdorferi*, the spirochetal cause of Lyme disease, may be negative at the time of the rash and is not needed for diagnosis of erythema migrans. Later objective manifestations of Lyme disease include arthritis (usually involving the knee or another large joint), carditis (usually manifested by second or third degree heart block) or neurologic involvement (which may be manifested by facial nerve palsy or lymphocytic meningitis). With these later objective manifestations, positive IgG *B. burgdorferi* serology is required to confirm the diagnosis of Lyme disease.¹³⁻¹⁵

What Are the Standard Serologic Tests for Lyme Disease? Serologic testing for *B. burgdorferi* antibodies consists of IgG and IgM enzyme-linked immunosorbent assay (ELISA) or immunofluorescence antibody (IFA). If the ELISA or IFA is positive or equivocal, then an IgM and IgG Western blot should be performed. Criteria have been established for a positive IgM Western blot (≥ 2 of the 23-, 39- and 41-kDa bands) and for an IgG Western blot (≥ 5 of the 18-, 23-, 28-, 30-, 39-, 41-, 45-, 53-, 56- and 91-kDa bands). For a patient to have positive serology, both the ELISA (or IFA) IgM or IgG and the corresponding Western blot IgM or IgG should be positive.¹³⁻¹⁶

What Other Laboratory Tests Are Useful for Diagnosing Lyme Disease? *B. burgdorferi* ELISA or IFA antibody determinations can also be performed on cerebrospinal fluid (CSF) samples. Intrathecal production of *B. burgdorferi* antibodies can be demonstrated by comparing antibody concentrations in the serum versus the CSF. *B. burgdorferi* can usually be cultured from skin biopsies of patients with erythema migrans. In acute disease, *B. burgdorferi* can be cultured from the blood (in large volumes), but it is very difficult to culture from joint fluid or CSF. PCR for *B. burgdorferi* is usually positive in the joint fluid of patients with acute Lyme arthritis. PCR for *B. burgdorferi* may be misleading if it is performed on blood or urine samples. Urine testing for *B. burgdorferi* (antigen or antibody) is not helpful.^{14,15,17-24}

What Is Chronic Lyme Disease and Does It Occur Commonly? Chronic Lyme disease is a term that is sometimes used to describe the rare problems of recurrent post-Lyme arthritis or chronic post-Lyme encephalopathy. In patients with recurrent Lyme arthritis, the initial positive *B. burgdorferi* PCR

of joint fluid often becomes negative after antibiotic treatment, although the joint effusion persists. Persistent *B. burgdorferi* infection in patients with chronic Lyme encephalitis has not been demonstrated. Chronic subjective problems such as fatigue, headache, irritability, poor concentration, poor memory, arthralgias or myalgias do not indicate chronic Lyme disease. Some of these subjective symptoms may occur after Lyme disease and may be termed "post-Lyme syndrome." These symptoms may be unrelated to Lyme disease and have not been shown to respond to antibiotic treatment.^{5,14,15,25-27} The Infectious Diseases Society of America practice guidelines do not include treatment options for chronic Lyme disease because persistent infection has not been demonstrated.⁷ Instead recurrent arthritis or chronic encephalitis could be termed post-Lyme disease problems. Thus chronic Lyme disease is a term that should no longer be used.

How Is Lyme Disease Treated? Oral antibiotic regimens for the treatment of Lyme disease of adolescents and adults include doxycycline (100 mg twice daily), amoxicillin (500 mg 3 times daily) or (if doxycycline and amoxicillin cannot be used) cefuroxime axetil (500 mg twice daily) for 10-21 days. Parenteral therapy options include ceftriaxone (2 g once daily) or penicillin G (18-24 million units once daily) for 14-28 days. Cefotaxime could be used rather than ceftriaxone. Combinations of antibiotics, prolonged courses of antibiotics or unusually high antibiotic doses should not be used to treat Lyme disease, because they may be harmful and have not been shown to be more effective than standard therapy.^{5,14,15,26-30}

If Lyme Disease Is Diagnosed and Treated in Pregnancy, Are There Dangers to the Fetus? If Lyme disease is diagnosed and appropriately treated during pregnancy, there is no reported risk of active *B. burgdorferi* infection in the fetus. There are 3 case reports involving pregnant mothers who had Lyme disease during pregnancy and who were not treated (or who were inadequately treated), and their newborns died within hours of birth with possible *B. burgdorferi* infections. There is no case of a newborn with symptomatic or asymptomatic persistent congenital *B. burgdorferi* infection. Congenital Lyme disease occurring after the immediate neonatal period has not been documented.^{5,15,31,32}

During or After Treatment of Lyme Disease, Is It Safe to Breast-feed? It is safe to breast-feed while being treated for Lyme disease. *B. burgdorferi* has never been cultured from human breast milk, and there is no case of an infant developing symptomatic or asymptomatic *B. burgdorferi* infection from breast milk.⁵

RESULTS

Using the above criteria, information was categorized as "accurate," "inaccurate," or "not addressed/not found." The content of the websites was evaluated on 3 separate occasions (January 2003, April 2003 and February 2004).

Table 1 summarizes the 19 websites evaluated by this study. Examples of inaccurate information are as follows.

What Should Be Done for a Tick Bite? Ticks other than the deer tick carry *B. burgdorferi*. A tick attached for <24 hours can frequently transmit Lyme disease. Antibiotic prophylaxis should be routinely prescribed for tick bites. Antibiotic prophylaxis for >10 days is recommended for tick bites.

How Is Lyme Disease Diagnosed? Diagnosis of Lyme disease may be based on subjective findings. Feeling better while being treated with antibiotics establishes the diagnosis of Lyme disease. Positive serology is not necessary to confirm the diagnosis of late Lyme disease (rheumatologic, neurologic or cardiac).

What Are the Standard Serologic Tests for Lyme Disease? Serology is unreliable even in late Lyme disease (rheumatologic, neurologic or cardiac). The CDC criteria for a positive *B. burgdorferi* Western blot is not useful for defining clinically infected patients with late Lyme disease. Symptoms and response to antibiotic therapy are more important than serology for confirming the diagnosis of late Lyme disease.

What Other Laboratory Tests Are Useful for Diagnosing Lyme Disease? A Lyme urine antigen test can be used to confirm the diagnosis of Lyme disease even with negative serology.

What Is Chronic Lyme Disease and Does It Occur Commonly? Chronic Lyme disease is common and occurs without objective findings. Chronic Lyme disease is caused by persistent *B. burgdorferi* infection.

How Is Lyme Disease Treated? Oral therapy may include antibiotics other than amoxicillin, doxycycline or cefuroxime axetil. Multiple antibiotics may be used simultaneously. Intramuscular penicillin therapy may be used. Parenteral antibiotic therapy (either iv or im) are commonly used along with

oral antibiotic therapy. Treatment courses longer than 28 days are usually needed, and courses of months to years may be necessary.

If Lyme Disease Is Diagnosed and Treated in Pregnancy, Are There Dangers to the Fetus? Many cases of congenital Lyme disease have been well-documented. Congenital Lyme disease can cause multisystem organ involvement for infants and children requiring prolonged therapy. Even if a mother is appropriately treated for Lyme disease during pregnancy, her newborn may still be infected and suffer from on-going infection.

During or After Treatment of Lyme Disease, Is It Safe to Breast-feed? *B. burgdorferi* can be transmitted via breast milk. A mother should consider not breast-feeding while being treated for Lyme disease.

DISCUSSION

Of the 19 websites examined, 9 gave inaccurate information concerning ≥2 of the 8 topics (Table). Eight websites contained the word “Lyme” in their name and 7 of these 8 gave inaccurate information. Of the websites that contained accurate information, 1 of 10 contained “Lyme” in its name. There were 2 “.gov” websites and both contained accurate information. Links occurred frequently among the inaccurate websites.

Previous studies have reported inaccurate medical information on the Internet. For example, when searching the Internet for vaccine information, websites advocating anti-vaccination positions were frequently found. These sites relied on anecdotal information and emotional pleas to convey their messages that vaccine risks outweigh benefits.³³ Another study showed that searching for information about

TABLE 1. Summary of Lyme Disease Information Given by 19 Websites

	Tick Bites	LD Diagnosis	Serology	Other Tests	Chronic LD	Treatment	Pregnancy	Breast-feeding
www.acponline.org	A	A	A	A	A	A	A	—
www.aldf.com	A	A	A	A	A	A	—	—
www.cdc.gov	A	A	A	A	—	A	—	—
www.fda.gov	A	—	A	A	—	A	—	—
www.healingwell.com	A	A	A	A	—	A	—	—
www.hopkins-arthritis.com	A	A	A	A	A	A	—	—
www.igenex.com	I	I	I	I	I	I	—	I
www.ilads.org	—	I	I	—	I	I	—	I
www.intelihealth.com	A	A	A	A	A	A	A	—
www.kidshealth.org	A	A	A	—	A	A	A	—
www.lyme.org	I	A	A	I	I	I	I	I
www.lymealliance.org	A	I	I	I	I	I	A	—
www.lymedisease.org	I	A	I	I	I	A	I	—
www.lymediseaseassociation.org	I	I	I	I	I	I	I	I
www.lymediseaseinformation.com	A	—	—	—	—	A	—	—
www.lymeinfo.net	—	—	I	A	I	—	—	I
www.lymenet.org	—	I	I	—	I	I	I	I
www.lymesite.com	I	I	I	—	I	—	I	I
www.webmd.com	A	A	A	A	A	A	—	—

LD indicates Lyme disease; A, accurate; I, inaccurate; —, not discussed or found.

illicit drugs (eg, cocaine, Ecstasy, etc.) yields websites that downplay dangers.³⁴

Beyond the risk of providing inaccurate health information, the Internet is problematic because of complexity. Websites that provide accurate medical information may be difficult for lay people to understand. It has been reported that many of the most credible websites that discuss medical information are written in complex technical terms and do not match with the varied reading levels of the lay public.³ Thus even accurate medical Web information can be misunderstood.

A study by Sood³⁵ examined the Internet and Lyme disease. Sood's³⁵ focus was to seek out those websites providing accurate Lyme disease information for health care providers and researchers. It did not address websites aimed at the public or sites that provide misinformation. Several of the websites examined in that paper require subscriptions and/or registration and thus are not available to the lay public.³⁵ <http://www.cdc.gov/ncidod/dvbid/lyme>, <http://www.aldf.com>, and <http://www.acponline.org/lyme> websites were reported as accurate by Sood.³⁵ These 3 sites were also found to be accurate in our study.

It is not unusual for patients and families to visit a physician with preconceived notions concerning the diagnosis and treatment of Lyme disease. These notions may be based on misinformation from the Web. The challenge for medical providers is to convince worried patients and families that some of the Internet-recommended testing and treatment of Lyme disease is inappropriate. This convincing can take multiple visits, debate, compromise and time.

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