



## **Lyme Disease Public Forum - Questions from April 29, 2006** as of June 9, 2006

*People living on Martha's Vineyard, and as far away as the West Coast, submitted almost one hundred questions to our speakers. Some were answered at the April 29 forum; many were not. This site is an effort to provide answers to all of the questions that were not addressed that day. There are still a few remaining questions. This site will be updated when answers are received. Submitted questions are not altered, with the exception of minor spelling changes, or small modifications of phrasing to clarify the intent of a question. The same is true for the replies of our speakers.*

*It is appreciated that there are divergent points of view regarding the answers to some of the following questions. The answers on this site are based on the experience and research of our speakers. The intent is to broaden our understanding about the diagnosis, treatment, and prevention of Lyme disease, and to enhance our respect of the diagnostic and treatment challenges this disease presents to patients and health care practitioners alike in the face of an evolving field of knowledge.*

*These answers should not be considered to reflect the opinion of the County of Dukes County, nor should a particular response be considered to reflect the opinion of each or any one particular speaker, unless otherwise noted.*

*Please check back periodically for new questions and answers. Also look for the MVTV broadcast of the public forum later this month. It is in the process of being translated with Portuguese subtitles. Thanks to our Public Forum moderator and speakers for their time and expertise: Dr. Bela Matyas, Dr. John Halperin, Dr. Robert Kalish, Dr. Sam Telford, Dr. Sam Donta, and Dr. Peter Krause – and to the individuals who submitted this excellent series of questions.*

**We (Martha's Vineyard) have more skunks, raccoons, squirrels, and other mammals per sq. mile. Do you conclusively know that the deer is the best/preferred host?**

A number of studies have demonstrated that deer indeed are the primary meal source for deer ticks, feeding more than 90% of all adult deer ticks. The adult female deer ticks are critical because they are the ones that lay the eggs from which all the deer ticks arise.

Adult deer ticks can be found in small numbers on raccoons, and even fewer on skunks. Adult deer ticks will not be found on squirrels, rabbits, rats, or mice. Raccoons and skunks are the source of wood "a.k.a." dog ticks.



**Do rabbits carry ticks in as great a concentration as deer?**

Rabbits are heavily invested with their own species of ticks. These ticks do not bite humans. Adult deer ticks are never found on rabbits.

**Can humans become infected with Lyme from direct contact with mice, moles, chipmunks, or other animals that infect ticks?**

No. Lyme disease requires infection by a deer tick. There are other infections that can be contracted from these animals. Therefore, best not to handle them.

**Is *Bartonella* found on Martha's Vineyard? Are doctors testing for it when they test for everything else related to tick bites? Should they?**

*Bartonella* may be found in all mice and in feral cats. Ticks do not transmit *Bartonella*, although some studies have reported finding *Bartonella* DNA in ticks. It is possible that people are exposed to, become infected by, and get disease from *Bartonella* BUT this is not associated with a tick bite.

Most probably, *Bartonella* is transmitted via flea bites. Bartonellosis typically presents with fever and enlarged lymph nodes, unlike the deer tick infections of Lyme diseases, babesiosis, and ehrlichiosis (anaplasmosis). Since fleas, not ticks, are likely to transmit *Bartonella* species, screening is not done when there is a tick bite, or when there is a suspicion of a tick-borne illness. Like tick-borne diseases, illnesses caused by *Bartonella* species are based on clinical history and exam, the tests just help confirm the diagnosis. Therefore, health care practitioners with an appropriate index of suspicion for these diseases would test and treat accordingly.

*Bartonella* may be cultured from blood to demonstrate active infection. Antibodies may be detected using available serology for cat scratch disease, the agent of which cross-reacts with mouse *Bartonellas* that are likely to be found on MV. As with many other tick-borne infections, a health care practitioner with a high index of suspicion for *Bartonella* as the cause of symptoms in an individual will likely recommend treatment, irrespective of testing. The urgency of initiating treatment depends on the underlying health status of that person and the severity of his or her symptoms. Testing could be undertaken to confirm the diagnosis. Testing can also be used to help diagnose a *Bartonella* infection in an individual with a mild constellation of symptoms that is not compatible with tick-borne illness. Bartonellosis may be treated with antibiotics in the tetracycline family.



**Is *Bartonella* found on Martha's Vineyard? Are doctors testing for it when they test for everything else related to tick bites? Should they? Continued...**

Given the prevalence of Cat-scratch disease, any patient with lymphadenopathy should be evaluated for exposure to this agent. Routine testing for infection by mouse *Bartonellas* seems premature until more information on the prevalence and clinical importance of this infection is accumulated.

**Please discuss the incidence and symptoms of *Bartonella*.**

*Bartonella* includes Cat-scratch Disease. As many as 25% of people in certain groups (veterinarians, for example) have positive tests for Cat-scratch disease. Mouse *Bartonella* probably causes human infection, but there are few studies of the incidence. There are fewer studies still of what exposure to *Bartonella* means to people, i.e. what kind of disease is typical with exposure. It is likely that *Bartonella* infection of any type causes fever, muscle aches, headache, fatigue, AND enlarged lymph nodes.

**What can be done to control the deer population on Martha's Vineyard? This is a public health emergency.**

Make it easier for hunters to do their job. Open up land for hunting. Talk to landowners who do not allow hunting on their land and convince them that even a couple of days of bow-hunting by experienced Island hunters can make a difference.

**If the deer population is reduced would it correlate with a reduction in tick-borne diseases?**

In the four studies where this has been done, the deer tick population decreased by an order of magnitude. This does not happen overnight. Deer reduction is a long-term strategy.

**Where did deer ticks come from? They weren't here before 1970 or so, only dog ticks were.**

Deer ticks were probably around in very small patches prior to 1970. They expanded their range as the deer herds grew and pasture turned into scrub oak forest. Naushon Island had deer ticks as early as 1922 because deer have always been there.



**Can you name a product that can be sprayed on clothing and will remain effective against ticks until the garment is laundered?**

Permethrin is a synthetic chrysanthemum extract that is very effective against ticks. Duranone is the most commonly bought brand name for permethrin. It is harmless to people. The U.S. Military puts this on their uniforms.

**My 20 year old daughter plans to do landscaping here this summer. How can she best protect herself?**

Anyone doing landscaping on the Vineyard should take the following precautions: Tuck trouser legs into socks, use permethrin on clothing and DEET on bare skin, and do a tick check every night. Before brush-cutting or lawn mowing, check the area for dead animals, never handle dead animals with bare hands, if a dead animal is found gloves should be worn and the animal cleared from the area either by burying it, or double bagging it and throwing it in the trash, for added protection a respirator can be worn if doing activities that will create dust. NIOSH certified or N-95 respirators should be used. It is important to remember that a respirator is only as good as its seal. **Any landscaper with an unexplained fever should see a health care practitioner.**

**What spray is best to use in your yard and grounds to protect against deer ticks? What do the Zane's use? What should be used where children play? What other outdoor preventive measures can we use?**

Professional pest applicators should be consulted. There are Island codes for permissible pesticides. Sprays are only temporary measures and could be used to protect guests for a backyard party or wedding. Damminix has been available for many years. Cotton balls are taken back to mouse nests and the ticks die on the mice. This does not get rid of all ticks, but it does take care of the ones that carry Lyme disease. This is because the deer tick larvae and nymphs feed on mice and get infected by *Borrelia burgdorferi*, the organism that causes Lyme. Damminix needs to be put out in the spring and fall every year. This is why a long-term solution should be something like deer reduction, rather than chemicals. Hunters reduce the deer heard for free. A homeowner pays every year for Damminix, MaxForce, or any other insecticide application.



**How should you dispose of a tick found in your home? Burn? Crush? Flush down the toilet?**

Ticks are very susceptible to drying out. Sticking them on scotch tape and disposing of them is fine. Do not crush a tick between your fingers; you can release the bacteria of an infected tick.

**If you find and remove a tick, should you seek medical treatment?**

If you find and remove a tick, you should contact a health care practitioner. Depending on the circumstances of the bite (i.e. when a person was bitten, the type of tick, how long it was attached), the health care practitioner may or may not choose to treat you.

In any event, whenever someone removes an attached tick from their body, they should monitor their health for the next month or two for the appearance of rash, fever or flu-like symptoms and immediately seek the advice of a health care practitioner should any of these symptoms occur.

**How can we get the pharmacies to carry tick remover kits and give appropriate advice about removing ticks NOT “just pull them out with Tweezers”.**

The Massachusetts Department of Public Health does not recommend any specific product for tick removal. There are many effective products available for removing attached ticks, including fine-point tweezers; it is important to remove the entire tick, including its head and mouth parts.

The decisions regarding which tick-removal products, if any, are carried by a pharmacy are made by either the specific pharmacy or its corporate manager. As a consumer, you can request that a specific product or products be carried.

In terms of giving advice, the pharmacist community could help by posting general educational materials on tick borne diseases. Try and encourage placement of this information in their store if they are not already doing so. The MDPH has posters, brochures, tick identification cards, and kiosk cards which could be distributed.

It is important to remove a tick as soon as it is found. Never crush the tick with your fingers. Using tweezers or a tick remover, grasp the tick close to where the mouth is embedded in the skin. Do not pull the tick out forcefully. Rather, pull with a steady pressure until the tick releases from the skin. After the tick is removed, wash the area with soap and apply some local antiseptic. Be on the look out over the next month or so



**How can we get the pharmacies to carry tick remover kits and give appropriate advice about removing ticks NOT “just pull them out with Tweezers”. Continued...**

for an expanding red rash, fever, or flu-like symptoms. If any of these symptoms develop contact a health care practitioner. If the tick was on for 36 hours or more and/or was engorged you should also contact a health care practitioner for a single dose of 200 mg of doxycycline for anyone older than eight years of age.

**If you have had Lyme disease does that mean that you will always test positive?**

Many people will continue to test positive for Lyme disease after complete eradication of the infection. This is why antibody tests should not be used by themselves to determine whether or not treatment has been effective. More information can be obtained by doing sequential or multiple antibody tests over time, such as every four weeks. Even then, the tests themselves may mean nothing unless the signs and symptoms are thought to be compatible with continuing infection by your health care practitioner.

**Should people living in an endemic area have a baseline test? If yes, at what age?**

Baseline tests are only useful if the tests will be done periodically, at a frequency of approximately every six months or less. If a baseline test is done in 2006, and you have not done any further testing, and then you develop an illness in 2009, a positive test would not help with confirming a diagnosis. This is because your “tick infection status” could have changed at anytime during those three years.

Now if you have a negative test at the beginning of the summer, have had some odd illness during the summer, and then you test positive at the end of the summer, that information *might* be useful to your health care practitioner if there are persisting signs and symptoms of tick-borne illness.

Usually baseline tests are done for occupational health programs. As for general population screenings for residents in endemic areas who may be exposed because of where they live or because of their recreational activities, this is a far more difficult question, not only for the reasons above, but also because it raises questions about costs and who keeps all this information.



**Should people living in an endemic area have a baseline test? If yes, at what age?  
Continued...**

Currently, there is no recommendation for baseline screening. The most important thing to remember is that Lyme and other tick-borne diseases are clinical diagnoses. The tests may support the diagnoses, but if a person has the signs and symptoms of one of these diseases, and there is a high index of suspicion that person indeed has a tick-borne illness, treatment will most likely be initiated even if the lab tests are negative.

**A doctor in Connecticut who deals exclusively with Lyme in children told me that the lab which the Vineyard doctors use to diagnose Lyme is inaccurate for a number of reasons. Are there significant differences in how different labs come to their conclusions? Can you comment on the Vineyard's testing?**

Differences exist between laboratories, although the differences are much smaller than they used to be. The experience of the lab and who advises the lab makes the biggest difference in accuracy of testing. Imugen is the lab that does much of the Vineyard's testing. Their tests' sensitivity (ability to pick up the presence of disease when it exists) and their tests' specificity (ability to rule-out the presence of disease when it does not exist) are very high. Additionally, Imugen keeps an individual's specimen for years. Therefore, they can compare a person's prior blood samples (if tested through Imugen) with a current blood sample when evaluating a person for a new or possibly recurring infection. Imugen's founder worked with Dr. Allen Steere to develop some of the first ELISA and Western Blot tests in the Country, over twenty years ago.

NOTE: The respondent to this question is an advisor to Imugen. However, he also serves as an advisor to several other laboratories besides Imugen.

**Is the multiplex PCR a definitive test? Can it indicate anything else?**

Very few labs have the experience to do the multiplex PCR properly; very few research labs use this technique because this technique can be unreliable.

**Why don't some insurances pay for home urine tests for Lyme?**

The home urine test has not been validated by independent scientists, the Centers for Disease Control, or by the Food and Drug Administration. Researchers do not use the test because it does not work reliably. If researchers won't use it, many insurers will be reluctant to pay for this test.



**It is my understanding that the CDC does not recommend any of the current Lyme tests to be used for diagnostic purposes because there are so many false negative tests when a person actually has Lyme. Is that true?**

Yes. Lyme tests should not be used to diagnose Lyme disease. Lyme disease should be diagnosed by health care practitioners based on clinical signs and symptoms. More properly stated: Lyme tests are used to confirm exposure to a deer tick infection in the context of compatible signs and symptoms. This has to do with something called “pre-test probability.” In other words, if you live in Alaska and have never been out of Alaska, and request a Lyme test because of flu-like symptoms, and the test comes back positive, that positive test is very likely going to be a “false-positive” test, meaning that the test is falsely positive even though there is no disease. That is because there are no human biting ticks in Alaska. So the “pre-test probability” of someone who has never left Alaska having Lyme disease is almost zero. Thus, these tests are only as good and as useful as the health care practitioner interpreting them.

**Ticks’ natural predators are hens, any thoughts of increasing their numbers? I for one would be willing to have them and try to convince my community throughout the island. Our island has many wild hens, which is also a possibility - to increase this population.**

Biological control has been a hope of many to address a number of pest problems. Unfortunately it usually doesn’t work too well. Yes, chickens will eat ticks, but they will eat any other arthropod too. Guinea fowl, pheasant, and young turkeys will eat ticks, but interestingly ticks will feed on the birds too. Several dozen deer tick nymphs have been seen on road-killed guinea fowl and pheasant. So the benefits of birds eating ticks might be counterbalanced by the ticks getting their blood meal from the birds themselves!

**How are the babesia bacteria different than the Lyme bacteria?**

There are several key differences.

Babesiosis is caused by an organism called *Babesia microti*. It is not a bacterium. Rather, *B. microti* is a protozoan parasite. Protozoa are single-celled animals. A parasite is a form of life that needs to live in or on a host, at the expense of that host. *B. microti* needs to live in red blood cells in order to replicate. Why this is an important health problem for humans will be explained a little later.



### **How are the babesia bacteria different than the Lyme bacteria? Continued...**

Lyme disease is caused by *Borrelia burgdorferi*. *B. burgdorferi* is neither a protozoon, nor a parasite. It is a type of bacteria called a spirochete because of its cork-screw shape. Like protozoa, most bacteria are also single-celled. However, because they lack a distinct membrane around their nucleus, they are not considered animals, and are thought to be more primitive than protozoa.

So why do *B. microti* parasites cause health problems in humans? When *B. microti* infects people, they enter their host's red blood cells in order to replicate. This process occurs at the expense of their host's red blood cells which eventually burst. Not only can this cause a severe anemia (a deficiency in the oxygen-carrying ability of our blood system), but once the new protozoa are released into the host's blood stream it kicks the host's immune system into action. That is what causes fever, sweats, chills, and other flu-like symptoms. People infected with *B. microti* may develop enlarged livers and spleens' the organs that try to clear the debris from the ruptured red blood cells. Occasionally severe infection may occur, causing damage to a host's kidney's, lungs, and/or brain. *B. burgdorferi* does not invade red blood cells. Rather it infects fixed tissues such as the skin, joints, heart, and nervous system.

*B. microti* and *B. burgdorferi* each have some distinct clinical features. For example, the invasion, transformation, and rupture of red blood cells occur in babesiosis, not in Lyme disease. The erythema migrans rash of primary Lyme disease or the secondary rashes of disseminated Lyme do not occur in babesiosis. *B. microti* and *B. burgdorferi* also share some similar symptoms. Almost everyone with babesiosis will have flu-like symptoms and about 20% of those with Lyme disease also will present with flu-like symptoms without a rash.

In general, young healthy individuals infected with *B. microti* do fine. Their immune system clears the infection on its own, either before they develop symptoms, or because their symptoms are so mild, they do not even realize they are infected by this organism. Other people develop flu-like symptoms, are diagnosed with babesiosis, receive appropriate antibiotic therapy, and clear the infection that way. Occasionally, young, healthy individuals have more severe symptoms, but generally the people who are at the greatest risk for severe, life-threatening complications are people over the age of 50, and especially people who are immunocompromised. Immunocompromised people have a hard time fighting infection because their immune systems do not work as well as those with healthy systems. Immunocompromised people are those who do not have a spleen, or who take immunosuppressive drugs, or who have a malignancy or HIV. These individuals may occasionally develop relapsing symptoms or complications from



### **How are the babesia bacteria different than the Lyme bacteria? Continued...**

babesiosis. In the case of Lyme disease, the complication rate is higher than with babesiosis—although that is changing with earlier diagnosis and treatment. Additionally, the diagnosis and treatment of persistent symptoms in Lyme disease is far more challenging than babesiosis.

### **If someone had babesiosis on screening for blood donation, but they never had symptoms, how should they be managed? Should they be treated?**

The test done for screening in blood donations is an antibody test. Antibodies are proteins that a person makes in response to an infection – in order to help fight that infection. Antibody against *B. microti* may remain in a person’s system for months, or even years, after infection. However, this does not necessarily mean that a person has an active infection, or that the parasites are still in that person’s body. An active infection is detected by seeing *B. microti* parasites in red blood cells on a blood smear and/or detecting *B. microti* DNA in blood using a PCR test (see below for a brief definition of this test).

It is important to remember that it is possible for the immune system of a healthy individual to clear a *B. microti* infection on its own – without antibiotics. Therefore, if a person was identified as having antibodies to *B. microti* on a blood donation screening, but currently has no symptoms suggesting active babesiosis, it is reasonable to try and confirm or exclude the diagnosis by doing some basic lab testing. This testing should include a peripheral blood smear to look for the parasites in red blood cells, and a PCR (polymerase chain reaction) test that looks for the *B. microti* DNA (genes) thus indicating the presence of the parasite. If both tests are negative in a person without symptoms, it is reasonable to do nothing else.

It is true that a single test alone may miss a person with an active, but low grade, infection, but this occurs in only a very small percentage of individuals. Sometimes if the antibody test is positive and the blood smear and PCR are negative and the person feels well, that person and their health care practitioner may decide to repeat the blood smear and PCR tests in three months. Usually, the signs of infection will completely disappear by then. If there is evidence for active *B. microti* infection at that time (meaning a positive smear or PCR), it would be reasonable to treat for babesiosis even if the person is asymptomatic and the number of infected red blood cells is very low. There is no hard data to support this approach, but it is certainly an option.



**If someone had babesiosis on screening for blood donation, but they never had symptoms, how should they be managed? Should they be treated? Continued...**

Things get a bit more complicated when someone with a positive antibody test has mild symptoms suggestive of babesiosis, but their peripheral smear and PCR test are both negative, especially when a patient does not have a spleen, or is over 50, or is immunocompromised. This is where it is important to have a good relationship with a health care practitioner. In such cases, the blood smear and PCR should be repeated right away. If positive, treatment should be given. If negative, other causes for the symptoms should be investigated.

**How sensitive are peripheral smears for babesiosis? How many times should a peripheral smear be repeated if it is negative and the index of suspicion is high?**

In general, peripheral smears are pretty sensitive for identifying parasites in red blood cells. However, a negative smear does not necessarily rule out infection, especially early in the course of the disease when the number of parasites may be small. If there is a reasonable suspicion that a person may be infected with *B. microti*, but has just a few mild symptoms such as fatigue or aches, it makes sense to repeat the test in a week or two. Remember though, that babesiosis, like most tick-borne diseases, is also a clinical diagnosis. If a person has symptoms and other lab tests suggesting active babesiosis infection and is clearly ill, one does not have to wait to see the parasites on the peripheral smear in order to start antibiotic treatment.

**If I have babesiosis am I now immune to getting infected again?**

It is not common to become re-infected again. There is no hard data about this, but anecdotally the re-infection rate is 10% or less. Most of these incidents are probably true re-infection. Much rarer is the reemergence of an existing *B. microti* infection. Bottom line: always use tick-prevention precautions and always check for ticks after possible exposure.

**Why is so little NIH research funding is given to the study of babesia, when the disease is known to be transmitted by blood transfusion?**

It is hard to say for sure, but one might guess there is not greater funding because the number of cases appears to be limited when compared to Lyme disease. This may change with emerging data about the increasing rate and geographic spread of babesiosis infections.



### **Do tick borne diseases present differently in children?**

Children usually have the same symptoms as adults **BUT** generally their symptoms are milder, and more often than not result in fewer complications.

### **What about in utero infection of undiagnosed Lyme, what are the consequences, treatment options?**

Most animal models do not show Lyme disease crossing the placenta and infecting the fetus from an infected mother - though it is hard to say this cannot ever happen. There were a few case reports in the 1980's that brought up the question of infection of a baby from the mother, but there have been few if any well documented cases of this since. The recommendations then are to treat Lyme disease in a pregnant woman as one would in anyone else excepting the need to not use certain antibiotics known to be contraindicated in pregnancy, such as doxycycline.

### **If you have a positive Lyme test while pregnant can that cause neurological damage either to the patient or the baby?**

If the test is positive because the mother has active Lyme (as opposed to prior infection) she has the same small risk of neurologic damage as anybody else with Lyme. There appears to be little if any risk of neurologic damage to the baby. If the test is positive because of past exposure, there appears to be minimal if any risk to mother or fetus.

### **I've heard that there are contradictory studies re: prophylactic use of antibiotics after a tick bite (i.e. taking 2 doxycyclines at once after removing a tick.) What is your advice, particularly with kids getting multiple bites over the summer? What about for children under age 8?**

No matter what age, if a person is bitten by a tick, call or see a health care practitioner. If possible bring the tick to the health care practitioner for identification. Remember, Lyme disease is transmitted by deer ticks only, and the risk of getting Lyme disease, babesiosis or human granulocytic anaplasmosis (ehrlichiosis) from a single deer tick bite is relatively quite low – approximately 1 to 3%. If someone has been bitten by a deer tick, and that tick was attached for more than 36 hours\*, and/or engorged, that person is at a higher risk for developing Lyme disease. Anyone in that category, who is older than eight years old of age, should get a single dose of 200 mg of doxycycline for prophylaxis against Lyme disease.



**I've heard that there are contradictory studies re: prophylactic use of antibiotics after a tick bite (i.e. taking 2 doxycyclines at once after removing a tick.) What is your advice, particularly with kids getting multiple bites over the summer? What about for children under age 8? Continued...**

Unfortunately, there is not a similar prophylactic option for children under 8 years old. In this case, the options are not straightforward. If a child falls into the high risk category, i.e. deer tick on for more than 36 hours and/or engorged tick, one option is to treat the child with 10 days of amoxicillin. The other option is to not treat, but over the next month or two to mindfully observe the child for signs of a red rash or flu-like symptoms. If these symptoms develop they should be reported to that child's health care practitioner. The same holds true for any individual with a deer tick bite whether given prophylactic antibiotics or not – monitor for the appearance of symptoms.

Note: There is nothing magical about the 36 hour mark. Infection can occur earlier in a small minority of cases. However, the likelihood of infection from a tick bite increases with increasing hours of attachment – see the following question. Again, whether or not prophylactic antibiotics are used, the person should be closely monitored for the next month or two for symptoms.

**Is it true that the tick has to be attached for 24 hours before it can cause Lyme disease?**

Animal models indicate the tick has to be attached for more than about 36 hours to transmit Lyme disease.

**I got a serious case of Lyme disease in 1977 and was never treated with antibiotics. After about 15 years the symptoms abated except for minor flare-ups. A recent blood test showed that I still have a Lyme antibody titer count. Does this mean that the disease is still present in my body? The same blood test showed an acute titer count for Ehrlichiosis. I do not understand how this can be possible because I have never had any sign of a tick borne disease since the original 1977 infection. Could you explain this?**

While it is not possible to address the specifics of any one person's medical experience without full knowledge of all the clinical details, there are several important issues that can be addressed from these questions.



**I got a serious case of Lyme disease in 1977 and was never treated with antibiotics. After about 15 years the symptoms abated except for minor flare-ups. A recent blood test showed that I still have a Lyme antibody titer count. Does this mean that the disease is still present in my body? The same blood test showed an acute titer count for Ehrlichiosis. I do not understand how this can be possible because I have never had any sign of a tick borne disease since the original 1977 infection. Could you explain this? Continued...**

First: Antibodies to *B. burgdorferi* can persist for a number of years and can do so even when there is no longer any infection by the organism. Some people have waxing and waning symptoms attributable to Lyme. Unfortunately, it is very difficult to demonstrate persistent infection, versus reinfection, versus persistent symptoms that are not due to Lyme disease. The only way to know for sure is to detect *B. burgdorferi* in a person's blood, spinal fluid, or tissue; not an easy thing to do. That is one of the reasons why there is so much controversy about the cause of lingering symptoms from Lyme disease.

As for the finding of an acute titer for ehrlichiosis (anaplasmosis), again without knowing the full details it is impossible to give a correct answer. Some possibilities include, (1) the test was incorrectly positive either because of test error or because of cross-reactivity of antibody tests for Lyme disease with those of ehrlichiosis (anaplasmosis), or (2) another tick bite caused an ehrlichia (anaplasma) infection that was undiagnosed, cleared on its own, but produced persistent antibody.

**How would you explain a case in which a patient was tick bitten and acquired several disease germs, including WA-1 babesia. The babesia was not diagnosed until four years later, with a positive blood smear, a negative B. microti antibody test, and a positive antibody test to WA-1 by the Sonoma County lab designated by the state of California to test for this parasite. The patient left the West Coast, has not returned since the tick bite, so this parasite remained present in the blood for years. Chronic babesia, not acute babesia. Is this unusual? It also took a lot more treatment than the books describe to get rid of this infection.**

Here too, we cannot address the specifics of any one person's medical experience.



**What happened to the Lyme vaccine? Was it ineffective? When will a new vaccine be available?**

LYMERix™, a vaccine for Lyme disease developed by GlaxoSmithKline Pharmaceuticals (GSK), was removed from the market on February 25, 2002. Questions about possible side effects and insufficient sales to make production financially sustainable led to its withdrawal from the market.

**Does having been vaccinated with the withdrawn Lyme vaccine increase the possibility of developing arthritis in those who had the vaccine?**

Though this has been claimed, and there have been theoretical concerns this could happen to date, to the best of my knowledge, it has never been documented that the Lyme vaccine triggers arthritis. In the actual vaccine trials there was not an increased incidence of arthritis.

**Is the ability to treat Lyme the reason more is not being done to develop a vaccine?**

That may be part of the answer. Another part of the answer is economic – see above. Despite these factors, there is considerable appreciation of the negative health impact of tick-borne illnesses including Lyme disease. Currently, there are a number of research efforts dedicated to developing vaccines to prevent not only Lyme disease, but the other diseases that are transmitted by *B. burgdorferi*.

**Why do vaccines work in dogs and not humans for Lyme?**

The human Lyme vaccine had an 80% efficacy rate, considered quite good for a bacterial vaccine. This vaccine was withdrawn from the market for the reasons cited above.

**How effective can antibiotics be for someone who has had Lyme for ten years?**

They may still be effective for an active infection of Lyme disease, even at that time. However, it is important to determine if the symptoms someone is having after that long a period is from an active infection versus what has been termed post-Lyme disease symptoms in someone who has already been treated with antibiotics for Lyme, or whether there is another cause of a person's symptoms - in which case antibiotics would not be expected to help.



**Can you please comment on the use of antifungal drugs like diflucan in the treatment of Lyme disease?**

Lyme disease is caused by a bacterium *B. burgdorferi*, not a fungus. Therefore, there is no direct role for antifungal medications such as fluconazole (Diflucan) for the treatment of Lyme disease. Indirectly, antifungal medications such as fluconazole may be used to treat yeast infections that can occur as a result of using antibiotics to treat Lyme disease.

**Is there difficulty differentiating between fibromyalgia symptoms associated with Agent Orange exposure and Lyme disease?**

The symptoms of fibromyalgia and chronic Lyme disease cannot be distinguished clinically.

**Is a spinal tap valuable when you have a weak antibody test?**

These two tests address two different questions. A spinal tap is useful in patients who appear to have active central nervous system inflammation, regardless of its cause. If somebody has such inflammation, and there are valid reasons to suspect Lyme, a spinal tap can be very informative.

**When a patient shows symptoms of Lyme with neurological issues, is a spinal tap a normal first step?**

This depends on the nature of the neurological issues. If there is evidence of central nervous system inflammation, a spinal tap can be quite informative. Normally the first steps are to establish if the patient has Lyme, and to do a careful neurologic assessment to establish what exactly is going on.

**Under what clinical circumstances is a spinal tap indicated in the work-up of Lyme disease?**

See answers to the above two questions.

**Are there studies showing a higher incidence of depression in patients with Lyme disease, or is it a consequence of prior infection?**

Several studies indicate that depression occurs with the same frequency in patients with Lyme as it does in other patients with prolonged inflammatory illnesses.



**How common is it for patients with Lyme disease to cry a lot and feel depressed?**

See the answer to the prior question.

**Can Lyme cause seizure-like symptoms?**

Yes, but this is extremely rare.

**Any updates on the relationship between *Borrelia* and Neurodegenerative diseases in the human host such as motor neuron disease, Parkinson's disease, multiple sclerosis, Alzheimer's disease, Lewy Body disease, Progressive Supranuclear Palsy?**

There are neither any data to support a link between *Borrelia* and these diseases, nor compelling theoretical reasons to believe such a link might occur.

**I suffer every year in December and January from re-occurring symptoms, without a new Lyme infection. Is my nervous system permanently damaged?**

I cannot answer this without knowing what the symptoms are. However I can think of no neurologic process that causes permanent damage and that leaves a person normal for 10 months of the year only to become symptomatic for two months of the year.

**Do spirochetes interfere with proper synaptic function? During active or late Lyme and during treatment I had pronounced episodes of mental reversals, ex. Thinking that the traffic is moving in the opposite direction than it should be. Is this a sign of active infection?**

The *Borrelia* spirochetes do not appear to have any direct effect on synaptic function. Some of the inflammatory molecules produced in response to any infection, including Lyme disease, can alter neurologic function temporarily.

**Should Bell's Palsy be treated with oral or intravenous antibiotics?**

Several European studies suggest either can be highly effective; whether either is more effective remains to be proven.



**Is there a role for a repeat course of antibiotics for neurological symptoms of Lyme disease?**

If the neurologic symptoms appear to be due to persistent inflammation & infection from Lyme disease, yes.

**Is it EVER possible for a person to have a negative ELISA for *Borrelia* in serum and a negative ELISA in spinal fluid, but also have a higher concentration (higher ELISA) in CSF (cerebrospinal fluid) compared to serum and therefore, have that as indirect evidence of reactivity to *Borrelia* in the CSF? Didn't you once have a patient like this where your comparison of CSF and serum on the ELISA lead you to clarification of the presence of *Borrelia* specific antibody production?**

I have seen one or two individuals with such numbers who I felt had Lyme; this is exceedingly rare and remains controversial.

**Why are patients told that their symptoms are “all in your head,” “post-Lyme syndrome,” or some neurodegenerative symptomatic diagnosis such as ALS, multiple sclerosis, Parkinson's etc, rather than Lyme disease?**

I can't speak to what words others choose. What appears clear is that most patients with persistent symptoms after apparently adequate antibiotics do not have an active brain infection and do not respond to more antibiotics. This does not mean their symptoms are fictitious or imagined; it does mean that something other than active Lyme infection must be responsible. Those who appear to have another type of neurologic disease almost certainly have that disease, as Lyme does not appear to cause any of them de novo. However, Lyme disease can worsen the symptoms of other neurologic diseases.

**Are any physicians on this panel aware of complementary treatments in addition to conventional antibiotics for preventing and healing the diseases that result from *Borrelia* organisms?**

I am aware of them and encourage their judicious use in conjunction with standard medical care in someone who is interested in pursuing complementary therapies. I feel these have their main role in trying to improve the symptoms that often follow Lyme disease (pain, fatigue, impaired sleep, etc) that I do not feel should be treated with antibiotics once the standard course of antibiotics have already been used. It is important to note that many of these therapies are not clinically validated. Although some complementary treatments can be helpful and even central as part of therapy and return to



**Are any physicians on this panel aware of complementary treatments in addition to conventional antibiotics for preventing and healing the diseases that result from Borrelia organisms? Continued...**

good health, there is also the chance that any particular alternative therapy is not effective or may be detrimental. **Note:** This is the response of one panelist. We will try and obtain responses from some of our other speakers.

**If a Lyme patient has a bad physical fall with a broken leg or hip, would this retrigger a bout of Lyme symptoms?**

Any joint affected with arthritis from Lyme or any other cause may worsen with trauma to that joint. However a fall or trauma itself should not by itself trigger a new bout of generalized symptoms from Lyme disease.

**What is the most effective antibiotic for chronic Lyme arthritis of the knee with high antibody titers (initial infection 15 years prior.)**

The recommended treatment for active Lyme arthritis remains one month of oral antibiotics with either doxycycline or amoxicillin regardless of how far out from the initial infection. If the arthritis has not responded to initial oral antibiotic treatment Lyme arthritis can be difficult to treat. Some advocate extending the oral antibiotic another month; a trial of intravenous antibiotics with ceftriaxone is also reasonable. If that still fails it may be that one has to treat with other modalities than antibiotics such as surgery or medications similar to those used for rheumatoid arthritis that suppress the immune system which may be overreacting in individuals with persistent symptoms.

**When is it reasonable to start a second course of antibiotic therapy for Lyme arthritis? When should one start IV antibiotics for Lyme arthritis?**

See answer to question above. Also many would say that one has to observe 3 months after antibiotic therapy to call a treatment for Lyme arthritis a success or failure. Even with killing of the bacteria in the joint, it may take a while for the body to clear all the debris and inflammation from the site of recent "battle" and for the joint to completely quiet down. My own practice is to extend immediately for another month the course of antibiotics if I see little or no improvement after the first month. Otherwise I wait two to three months before determining whether the treatment has worked or not. IV antibiotics remain an option for Lyme arthritis at any time after an oral regimen has failed - though the data are conflicting as to its chance of success in this setting.



**Are arthralgias from Lyme limited to extremity joints or are there symptoms in the spine with resultant degenerative changes?**

Lyme disease may cause transient symptoms of pain in the spine early in the infection as it can almost anywhere, but it should not cause lasting degenerative arthritis of the spine.

**In the published journal article which surveyed the Lyme, CT patients 10 to 20 years later, it was stated that the overall status of their health was good. How can this be true, when 58% of the facial palsy group reported memory problems, and 38% of the Lyme arthritis group now have chronic or episodic knee pain? This does not sound like a good outcome to me.**

In this study, it was found that Lyme disease does have significant sequellae (symptoms or conditions related to a disease) in some cases. As the questioner points out, a majority of patients who had facial palsy as part of their initial infection many years later subjectively answered yes to the question of whether they currently felt they had memory problems. However, formal memory/neurocognitive testing in these same individuals did not find objective deficits in their memory indicating evidence of true organic cognitive dysfunction or damage. Since many of these same patients also had experienced over the years a higher degree of aches and pains and fatigue the study attributed these results to be consistent with a post-Lyme syndrome as the best explanation for these findings.

Regarding the joint findings in patients who had arthritis, this was interpreted as indicating that the durations (months to years) of inflammation in the knee from Lyme arthritis had led to later mechanical problems in some of these knees. This is similar to what is seen in athletes for example who have ligament or cartilage injuries in the knee when young and are more likely to develop mechanical problems including degenerative arthritis in middle age. Therefore, the conclusions did not intend to dismiss that there can be later arthritic consequences of having had Lyme disease.

However two important points about this arthritis are: 1) these patients tended to have had Lyme disease that went untreated a lot longer than patients today. Many individuals in the study had Lyme disease in the era before antibiotics were standard therapy for Lyme disease. Therefore, we would expect a lower level of these consequences in individuals diagnosed with Lyme disease more recently; they typically receive antibiotics earlier in the course of their disease. 2) In spite of these symptoms, most of the individuals evaluated in the study functioned well in the years since their Lyme disease and indeed scored normally on many measures of health and function.



**When does “post-Lyme” syndrome begin? After any amount of treatment, whether it relieves symptoms or not? Is this standard applies to any other disease?**

There is no single accepted precise definition of when post-Lyme syndrome begins. As a general concept, one might say it begins when symptoms have lasted for more than several months, cannot be easily explained by an alternate medical disorder, are nonspecific and subjective (such as generalized aches and pain, fatigue or feeling mentally clouded), and significantly exceed in degree or severity that which is expected in a typical person recovering from Lyme disease after having received appropriate antibiotic therapy. This type of descriptive definition is similar to what may be seen in some people following other infections and may go by various names such as “post-infectious fatigue and pain syndrome”

**Is amoxicillin effective in this case? I was told I have only 3 of the 5 antibodies to make the Lyme test positive. I only tested positive once out of three Lyme tests. Yet, I exhibit chronic symptoms, Bells Palsy, chronic joint pain, and extreme lethargy. Doxycyline makes me vomit.**

Unfortunately without a full medical history and clinical examination it is not possible to comment on individual cases. However, a general point can be made that amoxicillin is an effective alternative treatment for Lyme disease for people who cannot tolerate doxycycline. Be aware that doxycycline treats both Lyme disease and human granulocytic anaplasmosis (ehrlichiosis); amoxicillin does not.

**Is the drug Ketek useful in the treatment of Lyme?**

Ketek (telithromycin) is a “cousin” of the erythromycin. Both are macrolides – a group of antibiotics that have been shown to be effective against Lyme bacteria in the test tube, but its clinical effectiveness in humans is unknown at this time. It probably is deserving of further evaluation. There have been some reports of liver problems and other potential toxicities with telithromycin. Anecdotal experience from seeing patients who have taken it for Lyme is that its use may be of questionable value.

**Have you correlated the increase in reported cases of diagnosed Lyme to an increase in the population of visitors (if there is an increase?)**

Lyme disease cases reported to the Massachusetts Department of Public Health are classified according the person’s county of residence, not their county of exposure. The increase in the number of Lyme disease cases seen in Dukes County reflects an increase among residents. It would not be correlated with an increase in the visitor population.



**What are the websites that you recommend for the public?**

Massachusetts Department of Public Health  
[www.mass.gov/dph/cdc/epii/lyme/lymehp.htm](http://www.mass.gov/dph/cdc/epii/lyme/lymehp.htm)

**Note:** MDPH is unable to vouch for the accuracy of information available on websites other than MDPH's, but many other sites also contain a lot of useful information, including these:

Centers for Disease Control and Prevention  
[www.cdc.gov/ncidod/dvbid/lyme/index.htm](http://www.cdc.gov/ncidod/dvbid/lyme/index.htm)

University of Connecticut Lyme Disease Education Home Page  
[www.ucc.uconn.edu/~wwwlyme/index.html](http://www.ucc.uconn.edu/~wwwlyme/index.html)

American Lyme Disease Foundation  
[www.aldf.com/](http://www.aldf.com/)

Iowa State University (Good site for tick photos)  
[www.ent.iastate.edu/imagegallery/ticks/deertick.html](http://www.ent.iastate.edu/imagegallery/ticks/deertick.html)

**Note:** This is the response of one panelist. We will try and obtain responses from some of our other speakers.