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To: Interested 10th District Constituents

From: Rep. Frank Wolf Date: September 2008

Re: Lyme Disease Forum/ Follow-up Questions

With such a large turnout at the Lyme Disease Forum last month, we couldn't get to everyone's question. As promised, below please find follow-up questions submitted to my office via e-mail message. These questions were forwarded to our speakers, and then compiled into a general question and answer list without names for posting on my congressional Web page (www.wolf.house.gov).

- Q: During the presentation there was mention of a Lyme Disease Immunization which was pulled from the market a few years ago. I wanted to ask why that occurred and if any pharmaceuticals are working on a reformulation and re-release anytime soon.
- A: The vaccine for Lyme disease, LYMErix, was voluntarily removed from the market by its manufacturer SmithKline Beecham in 2002, citing low demand for the vaccine and concerns raised about adverse effects from the vaccine. More information on this is available from the CDC at http://www.cdc.gov/vaccines/vpd-vac/lyme/default.htm. I am not aware of any new vaccines planned on being released in the near future. (*Dr. David Goodfriend, Loudoun County Public Health*)
- A: As I understand, there were unacceptable side effects that caused this to be pulled. No other projects are near to being available as far as I am aware. (*Dr. Samuel Shor*)
- Q: I was diagnosed with acute Lyme disease but the antibiotics prescribed did not cure all of my symptoms. Why is doxicyclene still the drug of choice when it is known that it does not cross the blood brain barrier?
- A: Doxycycline is the drug of choice for early Lyme disease. For neurologic disease other than Bell's palsy caused by this infection, cetriaxone is usually the drug of choice. More information on the treatment of choice at each stage of Lyme disease is available in the May 23, 2005 issue of the Medical Letter available online at www.cdc.gov/ncidod/dvbid/Lyme/resources/1209Lyme.pdf (Dr. David Goodfriend, Loudoun County Public Health)
- A: Unfortunately, doxycycline may very well not be adequate for either Bburgdorferi, the organism responsible for Lyme, or all of the other potential coinfections. In addition, the dose of 200mg twice daily recommended by ILADS is not usually recommended elsewhere. (*Dr. Samuel Shor*)

Q: Are there any other treatment that can be used if you are allergic to the antibiotic treatment?

- A: Amoxicillin and cefuroxime axetil (CeftinR) can be used if the person is allergic to doxycycline. (*Dr. David Goodfriend, Loudoun County Public Health*)
- A: There are multiple antibiotics that could potentially be used. There are also nonFDA approved supplements that are often used, but not as well studied.(*Dr. Samuel Shor*)

Q: Can you still have children if you have Lyme disease? Will this affect the pregnancy and/or giving Lyme to your unborn children?

- A: According to the CDC, untreated Lyme disease may cause problems during pregnancy, but there have been no documented cases of a negative effect on the fetus when the mother receives appropriate antibiotic treatment. There are also no reports of Lyme disease transmission from breast milk. More information on the transmission of Lyme disease is available at www.cdc.gov/ncidod/dvbid/LYME/ld transmission.htm. (Dr. David Goodfriend, Loudoun County Public Health)
- A: If a woman has active Lyme then there is a moderate risk of transmitting to the unborn child. This risk goes to virtually zero if appropriate antimicrobials are used during pregnancy. (*Dr. Samuel Shor*)
- Q: Our grown son had a positive test for Lyme but the infectious disease doctor is sending him to a rheumatologist. He was on doxycycline for three months and the pain was gone, but now it has returned. Is this the way to proceed and can Lyme still be present?
- A: It is always possible for the disease to still be present even with appropriate antibiotic therapy. It also possible to be reinfected with the infection that causes Lyme disease. It is important, though, not to overlook other potential causes for joint pain, for which a rheumatologist would be the specialist of choice.(*Dr. David Goodfriend, Loudoun County Public Health*)
- A: A return of symptoms is probably due to an inadequate treatment of the underlying infection and/or coinfections and would warrant further management. (*Dr. Samuel Shor*)

Q: Is it possible to get a complete list of doctors in our area who are Lyme literate?

- A: As Lyme disease has become more prevalent, more and more of our health care providers are becoming increasingly knowledgeable about Lyme disease. People with symptoms of early Lyme disease should see your primary care provider and seek referral if needed. (*Dr. David Goodfriend, Loudoun County Public Health*)
- A: Contact the International Lyme and Associated Diseases Society at www.ilads.org (Dr. Samuel Shor)
- Q: I have a 2-year-old daughter with Lyme. Are doctors in Loudoun being taught/directed to look for Lyme in children, given the increased incidence of this disease?

A: As Lyme disease has become more prevalent, more and more of our health care providers are

becoming increasingly knowledgeable about Lyme disease. This is particularly true of our pediatricians, given the disproportionate number of those under age 18 who are diagnosed with Lyme. (*Dr. David Goodfriend, Loudoun County Public Health*)

- Q: Is there any major research or treatment center in the U.S. for inpatient assessment and treatment for Lyme?
- A: The National Institute of Allergy and Infectious Diseases (NIAID) at the National Institutes of Health (NIH) has a Lyme Disease Research Program dedicated to developing better means of diagnosing, treating, and preventing this disease. To accomplish these objectives, the NIAID Lyme disease research portfolio includes a broad range of activities designed to increase our understanding of this disease. For additional information please visit the NIH Web site at, http://www3.niaid.nih.gov/topics/lymeDisease/. (Dr. Samuel Shor/Congressman Wolf's Office)
- Q: What can out-of-state residents do to receive more consistent and more frequent physician appointments when Lyme is not officially addressed in their home state?
- A: Try lobbying your legislators and your health department. Many times the media will pick up a story. This gives good coverage.(*Dr. Jorge Arias, Fairfax County Public Health Department*)
- Q: When we find a tick that is attached what is the best thing to do with it? Should we get it tested and by whom? Are there labs in the area that test ticks for Lyme bacteria?
- A: One of the best things is to get the tick identified. Fairfax County Health Department offers that service to its residents. If it is not a deer tick it will not transmit Borrelia burgdorferi. If it is a deer tick and has been attached for some time, take it to the doctor with the identification. Some people don't recommend tick testing; others do. In general, the CDC does not recommend testing ticks, as it is not useful for deciding if a person should get antibiotics following a tick bite. (*Dr. Jorge Arias, Fairfax County Public Health Department*)

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