

## Powerful Patient #30, 2008 Week 24

Host: Joyce Graff, WebTalkRadio.net

### Pitfalls on the Road to Diagnosis

Joyce Graff speaks with T. L. Kittle, who has Lyme Disease, about her difficult journey to diagnosis and the pitfalls along the way: false negative test results, the veto power of the insurance company, and legal constraints blocking the doctor from fully utilizing experience and instinct and patient input.



Tara Leigh Kittle

#### 1) About Our Guest

**T. L. Kittle** works in the entertainment industry in Los Angeles. In 2004, while in the midst of writing and directing her first feature film, Kittle was bitten by a tick. Soon afterwards, she began experiencing strange health symptoms such as fatigue, joint aches, then later a dry cough that wouldn't go away along with a pronounced muscle twitch on the right side of her face.

Deep in the midst of production with many responsibilities, she felt she was too busy to take time to see a doctor...until things finally got to the point she couldn't stand for more than five minutes, developed a heart murmur, and ended up with lesions throughout her brain. After countless doctor visits, she was finally diagnosed with Lyme Disease, which slowly led her down the pathway to recovery

#### 2) About the pitfalls

We discuss the room for error in medical testing. Every test has a statement of its **effectiveness** which is packaged with the test, or available from the lab, or indeed on the internet. It is usually phrased as "80% accurate". Subtracting from 100%, that tells you the range of its inaccuracy – in this case, 20%. So 20% of the time, it will fail to give the correct answer. It may say YES when the real answer is no (false positive), or it may say NO when the real answer is yes (false negative). Practicing medicine on the basis of test results alone sentences patients like T. L. Kittle to suffer unnecessarily until they are fortunate enough to find a doctor who is willing to step outside of the limiting boundaries of test results—and practice medicine clinically.

Beacuse she was already quite ill by the time she finally started to seek medical care, her case was also complicated by the complexity of the symptoms she was experiencing, as well as the range of exposure to possible diseases she had encountered while making her film. Since Tara had been exposed to a bat, she was given preventive (or prophylactic) treatment for **rabies**. There is no cure for rabies. While the disease is very rare, any kind of exposure to a bat mandates preventive ("prophylactic") treatment. There is good information about Rabies at <http://www.dhpe.org/infect/rabies.html>, and more

information available from the U.S. Center for Disease Control, at <http://www.cdc.gov/rabies/about.html>

Another major pitfall for Kittle, was the number of other unusual responses she had to diseases. At one point during the fall of 2005 (when she was the most ill), she developed **bacteremia**, which is a potentially life-threatening bacterial infection in the blood. Because her body doesn't mount the expected immune response, her basic bloodwork came back negative, and she looked 'healthy' the day she was diagnosed. However, a culture of her blood came back positive (which means the lab found bacteria growing in her blood), confirming her pleas to her doctors that she was dying.

### **3) About Lyme Disease**

Since she had been shooting her film in the Midwest, it was suspect early on that she might have Lyme Disease, but the standard tests kept coming back negative. Unfortunately, some people who have false negative tests for Lyme Disease end up in a wheelchair, deathly ill, or even die from the disease. Misunderstanding by physicians about the disease and the unreliability of the test results combined with the stifling legal structure is leading to a lot of unnecessary harm—to the people who are in need of medical care but can't get it due to false negative results.

For more information about Lyme Disease:

California Lyme Disease Association:	<a href="http://www.lymedisease.org">http://www.lymedisease.org</a>
U.S. Center for Disease Control:	<a href="http://www.cdc.gov/ncidod/dvbid/lyme">http://www.cdc.gov/ncidod/dvbid/lyme</a>
The Lyme Disease Network:	<a href="http://www.lymenet.org">http://www.lymenet.org</a>
The Lyme Disease Association:	<a href="http://www.lymediseaseassociation.org/">http://www.lymediseaseassociation.org/</a>
Wikipedia:	<a href="http://en.wikipedia.org/wiki/Lyme_disease">http://en.wikipedia.org/wiki/Lyme_disease</a>

### **4) About Wellness Care**

One of the Eight Ways you can help your doctor save your life is to show up at the doctor's office—not only when you are sick, but once a year for a wellness checkup. As Kittle says in this interview, a yearly doctor's appointment establishes a relationship between you and your doctor, forming a baseline which allows your doctor to compare your symptoms when you become sick. Building this relationship over time also allows the doctor to build trust in you, so the day when you walk through the door and say, "Something is wrong with me", they know it's true and work you up right away.

As the gatekeeper for your insurance company referrals, your General Practitioner (or "Primary Care Physician") should be the physician who knows you as a whole person—not just as a single bodypart, as a specialist may see you ("a heart patient" or "a kidney patient"), but as a whole person with a brain and a level head who is taking responsible action toward your health—and this begins by seeing him or her once a year when you're healthy. This way, when the time comes when you do need medical action, the doctor will be better prepared to help you.