

Talking Points for LD Awareness Week

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If you talk with the media, it's important to stick to the main points that are easily understandable to the listening/reading public, and not go too far down the path of tragic personal story and obscure (although *to us* interesting) facts about *Borrelia burgdorferi*, cyst forms, persistence, etc. Pretend you are talking to an intelligent eighth grader and have to stick to the most basic facts. Assume they have not been immersed in Lyme disease for months or years and are coming to it cold. Bring them round gently by using concrete facts and comparing Lyme to other, more familiar topics. The points below may help you. Don't try to cover all of them – pick your favorites. Another strategy is to keep a Lyme brochure in front of you and try to cover all the bases without going into too much detail at any one stop.

If a reporter asks a question that puts you on the spot, or makes you feel defensive, or makes you think you might have to give an answer that would hurt rather than help Lyme patients, take a deep breath, then say, “What you should be asking is....” In other words, reframe the question and then answer your own question. I'll put examples of these questions at the end, or you can make up your own.

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- Lyme disease is almost eight times more commonly reported than West Nile Virus in the U.S., yet the government spends **18 times** more money on each case of WNV.
- In 2004, the CDC reported an estimated 19,804 cases of Lyme disease. The CDC admits only 10 percent of cases meeting its criteria for Lyme disease are reported. This means that 198,040 new cases meeting the criteria occurred in 2004 in the U.S. This doesn't count cases that are never reported (which a Georgia study suggests are **40 times** the reported numbers) and it doesn't count cases that are misdiagnosed with another Lyme-mimicking disease like fibromyalgia, chronic fatigue, MS, depression, and even mental illness and hypochondria. Multiplying 198,040 by 40 gives almost **eight MILLION** cases per year, and no one knows how many undiagnosed cases there are. Millions more.
- According to a study published in 1993 in *Contingencies*, an actuarial trade publication, the cost to society for Lyme disease was about one billion dollars per year. Cases have doubled since then, so today's costs are probably \$2 billion or more annually. The average treatment and diagnosis and lost wages related to Lyme disease was **\$61,688 per year per patient**. [You can mention your own costs.]
- Children are in the highest risk category for contracting the disease (25% of total reported cases). A CDC study reported that a child with Lyme in New Jersey has a median school absence of **140 days**. A Columbia University Medical Center study reported one child had a **22-point drop in IQ** from Lyme.
- The ELISA test is unreliable and **misses as many as 35%** of culture-proven Lyme (only 65% sensitivity). By definition a screening test should have 95% sensitivity. Yet this is the test used most often by doctors, and patients who are not positive are denied diagnosis and treatment.

- If you had cancer, the doctor would tell you about the benefits and risks of different treatment options and let you choose. This is called “informed consent.” People with Lyme **should also be able to choose** the treatment they prefer, whether short or long term, oral or intravenous, one medicine or many. Yet doctors are being prosecuted by their state medical boards for treating Lyme patients with aggressive, long-term treatments, and insurance companies are refusing to pay for what the doctor orders, in spite of the fact that studies consistently show **high failure rates**, ranging from 26% to 50%, using short term antibiotic approaches.
- Ticks that have been attached only a short time CAN transmit disease. In one study, 11% of mice became infected after **only two days** of tick attachment (less than 48hrs.) and one report documents infection after less than six hours of attachment. Almost **100%** of infected nymphal ticks attached until they fall off will transmit the infection.
- According to a CALDA survey, the misapplication of CDC surveillance criteria (either ELISA or WB) for diagnostic purposes resulted in a delay in diagnosis of one year or **more for 49%** of responding patients. The average period of delay in diagnosis was almost **4½ years**. A full 81% of patients had physicians fail to diagnose their Lyme disease because of misapplication of the CDC surveillance criteria for diagnosis. Many of these patients incurred treatment delays as well.

Sample questions for “re-framing” the conversation

- Why do people with Lyme disease sometimes have to travel hundreds of miles, even out of state, to find a doctor willing to diagnose and treat them?
- Why do people with Lyme disease sometimes have to wait months for an appointment?
- Why are medical boards in some states prosecuting Lyme doctors for trying to help sick patients?
- Why is the government supporting treatment guidelines that are known to have a high failure rate (26 to over 50%) when better alternatives are available?
- Why is the government giving so much money to diseases like West Nile Virus, which affects far fewer people than Lyme disease, or bird flu, which humans don’t even get, compared with Lyme disease which can cause disability comparable to congestive heart failure and costs billions of dollars annually?
- Why did I have to wait ___ years to be diagnosed when early diagnosis and treatment might have prevented years of pain and suffering?
- Why do doctors categorically tell people “You can’t have Lyme,” when there is no test that can reliably exclude it, and it has been found in all but one state in the US (Montana)?
- Why did the medical society that composed the most influential guidelines (IDSA) that most doctors follow have “defeat patient-sponsored legislation” as a top agenda item at their annual 2005 meeting?