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Lyme Disease Talking Points

Based on comments by Dr. Dan Kinderlehrer on the Today Show, June 10, 2002

- 1: Lyme disease is an epidemic, already the fastest growing in the U.S., with new cases surpassing AIDS. It is particularly bad in the northeast, upper Midwest and northern California, but the disease is virtually everywhere, having been reported in 49 states. At present 180,000 cases have been reported to the CDC, but even by conservative estimates this figure is probably off at least 10-fold; the actual number of cases may be closer to 100-fold greater.
2. The epidemic proportions of this illness are staggering, but are being minimized by the government and insurance industries because of the financial implications. In the meantime, doctors who are aggressively diagnosing and treating this infection are being harassed by state medical boards; 2/3 of Lyme-treating docs in NY state are under investigation. The government tried to shut down one of the few labs that specializes in Lyme diagnosis. They have succeeded in shutting down another. Medical journals are selectively publishing poorly executed studies suggesting that Lyme disease is "hard to catch and easy to cure"; thus insurance companies don't have to pay for long-term treatment.
3. Chronic Lyme-disease is a catastrophic illness. It affects mainly the musculoskeletal system, the nervous system, and the heart. Its manifestations can mimic chronic fatigue syndrome, fibromyalgia, rheumatoid arthritis, systemic lupus, multiple sclerosis, Parkinson's disease, Lou Gehrig's disease (ALS), paralytic syndromes (e.g. stroke), brain tumors and others. It can cause severe depression and psychosis ("it's hard to fight an enemy that has outposts in your brain." According to one victim), and has resulted in suicides. Residents of psychiatric wards have a high percentage of Lyme-positive blood tests. This is a bad disease, and most of its victims remain misdiagnosed and untreated.
4. Most doctors are painfully unaware of how to diagnose or treat Lyme disease properly. There have been many cases of people with fairly obvious infection, but their doctors totally and inexplicably missed it. Not just country docs, but also physicians in places like the Mayo Clinic and the New England Medical Center. This despite their living and practicing medicine in Lyme-endemic areas.
5. Lab tests stink. Doctors mistakenly depend on these tests to make a diagnosis, but the CDC makes it clear that Lyme disease is a clinical diagnosis based on history and physical exam, and the lab tests can confirm but not rule out this infection. The Lyme disease spirochete has devised ingenious ways to elude detection by our immune system, and most laboratory tests don't fare any better. Nevertheless, doctors routinely rely on the lab data, and suggest to many of their multi-symptomatic patients that their problems are psychological in origin.
6. The deer-tick is a veritable cesspool of germs. Probably most people with chronic Lyme disease have co-infections with other microbes, such as Babesia, Ehrlichia and Bartonella. Multiple infections have an immunosuppressive effect, making it even harder to treat the Lyme disease. Doctors know even less about these other infections.
7. Antibiotics are important and occasionally life-saving. If given soon after the tick bite, they are fairly effective. However, once Lyme disease becomes chronic (particularly if the infection is more than a year old) it is difficult for antibiotics to clear it, in the same way that tuberculosis and other chronic infections may be difficult eradicate. Many people have been taking antibiotics for years, even intravenously. Adjunctive treatments for chronic Lyme disease, such as hyperbaric oxygen, cholestyramine and immune modulation, are being investigated on a limited basis, but research funds for all forms of Lyme disease treatment are essentially nonexistent.
8. For more information about Lyme disease and other tickborne infections, please visit the following websites.

Lots of Links on Lyme Disease - www.geocities.com/HotSprings/Oasis/6455/lyme-links.html
Lyme Disease Foundation - www.lyme.org

Lyme Disease Network - www.Lymenet.org
IgeneX Laboratory - www.igenex.com