

# Chronic Lyme Patients Can't Get Treated CDC Director Told by National Patient Group

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For Immediate Release

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## Chronic Lyme Patients Can't Get Treated CDC Director Told by National Patient Group

Lack of treating physicians, inadequate testing, and under diagnosis are leading to more chronic Lyme disease with surveillance problems contributing to lack of focus & funding

JACKSON, New Jersey (July 19, 2006) –Lyme patients have fought for years to have their public voice heard by the Centers for Disease Control and Prevention, CDC. They finally got their opportunity when the Lyme Disease Association, a national non-profit consisting of patients and families of patients, met with the nation's leading public health officer, CDC Director, Dr. Julie Gerberding. She and other CDC officials listened as the Lyme Disease Association and four Congressmen addressed rising Lyme cases, chronic disease and causes, inability to get treatment, and lack of funding. The government only expends ~\$33M each year on Lyme disease despite about 220,000 new cases of Lyme disease nationally that meet CDC surveillance criteria. That does not even include cases, usually chronic, which fall outside that non-diagnostic criteria.

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Dr. Brian Fallon from Columbia University College of Physicians and Surgeons presented long-term Lyme disease treatment studies and their significance, including his recently completed NIH-funded chronic Lyme

disease study showing improvement in patients. LDA president Pat Smith discussed the need for direct communication between patient groups and the CDC and between treating physicians and the CDC. Congressman Christopher Smith (no relation) offered to host a forum for those issues in New Jersey.

Ms. Smith presented the need for mandatory lab reporting in each state, uniform surveillance, and a dual CDC reporting system allowing for clinical cases to be accepted in a separate tier of reporting. She also recommended removing the ELISA as a screening test due to its insensitivity and allowing the Western Blot to be used alone for diagnosis, after re-adding two bands removed by CDC in the mid 90's. "New technology also needs to be looked at in the testing arena," Smith added, referring to a recently published CDC article on chronic diseases and the use of cutting edge technology to diagnose. Researcher Dr. Steven Schutzer, New Jersey Medical School, who also attended, affirmed that need.

Ms. Smith asked the CDC to write every state health department informing them that the CDC criteria are not meant for diagnostic purposes, only for surveillance. Health departments can then notify physicians in their states. "Too many people," she said, "are being refused diagnosis, treatment, and insurance reimbursement based on surveillance criteria. This is leading to a huge increase in chronic disease, costing people their health, homes, jobs, education, and childhood." LDA presented a comprehensive notebook including statements from dozens of Lyme patients attesting to their diagnostic and treatment problems often related to CDC surveillance criteria.

Lorraine Johnson, JD, MBA, Executive Director of CALDA and Member of the LDA Professional Advisory Board, spoke about peer review and guideline issues. Her main thrust was explaining how unsettled science and two sets of treatment guidelines have led to two standards of care, and all physicians need to be aware that there is a standard which allows for long-term treatment of chronic patients. "What we would like to see is for the CDC to treat Lyme disease the

same way it treats prostate cancer—providing patients with information regarding treatment options until the science is more settled,” she said.

The LDA-initiated meeting was hosted by Congressman Christopher Smith (R-NJ). Other US Representatives who personally attended were Congressman Tim Bishop (D-NY), Congresswoman Sue Kelly (R-NY) and Congressman Wayne Gilchrest (R-MD). Each spoke about rising Lyme disease cases in his/her state and personal experiences through family and friends with the disease. Staff from the offices of Senator Christopher Dodd (D-CT) and Senator Chuck Schumer (D-NY) also attended the meeting.

Dr. Gerberding agreed that tick-borne diseases are very complicated diseases that are poorly understood. There is a lack of awareness and early primary care is critical. Her concern that there is little government funding for tick-borne diseases dovetails with the purpose of the bills currently in Congress, HR 3427 (Smith-Kelly) and S 1479 (Dodd-Santorum) which will provide \$100 million for Lyme disease research, prevention, physician education, and surveillance issues. 73 congressmen currently co-sponsor the House version and over 100 Lyme groups support it.

In closing, the LDA mentioned the unchecked spread of the deer tick populations nationwide over the past 20 years and how we need to learn from history and try to stop the spread of the more aggressive lone star tick now invading the Northeast.

The CDC is now reviewing the recommendations made by the Lyme Disease Association.