

For Immediate Release

**Lyme Advocates & Patients to Protest CSTE Conference in Atlantic City**  
Amendment Would Artificially Lower Number of Lyme Cases

**June 26, 2007** – Lyme patients representing families from across the country will gather outside of the Convention Center in Atlantic City (NJ) on Wednesday afternoon, June 27, to protest Lyme disease surveillance changes being voted on at the Council of State & Territorial Epidemiologists (CSTE) conference. The protest, organized by members of LymeRights, a grassroots patient advocacy group, objects to proposed revisions to the present Lyme disease surveillance criteria. According to LymeRights, the revision will falsely lower case numbers nationally. Of particular concern are restrictions that will impact states with emerging Lyme disease.

The 2007 amendment being considered, “Revised National Surveillance Case Definition for Lyme Disease” (07-ID-11), would alter the existing requirements for diagnosing based on the erythema migrans (EM) rash, presently considered definitive for Lyme disease diagnosis. Patients who develop an EM rash in non-endemic states -- those just beginning to be touched by this national epidemic -- will now be required to demonstrate additional proof, a positive test, before a case can be counted,. Advocates fear this change will result in more missed cases, delayed diagnosis and serious long-term illness for many patients, and it will “lower” reported confirmed case numbers nationwide. Lyme Rights is calling for heightened awareness and fewer obstacles to diagnosis and prevention.

Concerns that the changes proposed in these new guidelines could undermine the Centers for Disease Control & Prevention (CDC) goals of defining the geographic distribution of Lyme, monitoring disease trends, identifying risk factors for transmission in areas where Lyme disease is newly emerging and measuring the public health surveillance burden over time were outlined for the CDC by leaders in the Lyme community this week. A letter opposing the proposed revisions being presented by CSTE member Matthew Cartter (CT) was sent to CDC Director Dr. Julie L. Gerberding. and signed by the Lyme Disease Association (LDA), the national patient organization, representing the other

organizations who signed in support including the International Lyme and Associated Diseases Society (ILADS), a professional medical society, and dozens of advocacy groups nationwide.

According to the letter, “it [proposed revision] dilutes **confirmed** cases by restricting the use of EM in diagnosis, which will lead to many current **confirmed** cases reclassified as **probable** and lead to many cases in the south and west never being reportable. “

The letter was also sent to the CSTE.

LDA President Pat Smith told LymeRights “The adoption of this revision will be a giant step backward for Lyme disease reporting, requiring patients who get bitten in specific areas to have a positive test in addition to the rash. As always, the patients will be the ones who suffer the most, since the surveillance criteria are already used improperly and extensively as a basis for diagnosis, treatment, and denial of reimbursement despite CDC warnings that the criteria are to be used exclusively for surveillance. “

LymeRights believes that prevention is only possible when the risks of acquiring a disease are clearly understood by health care professionals and the public. According to a report issued this month in MMWR by the CDC, reported cases of Lyme disease have more than doubled since 1991. The greatest concentration is now in 10 Northeastern, Mid-Atlantic and North-Central states but during 2003-2005, 64,382 Lyme disease cases were reported to the CDC from 46 states and the District of Columbia. Reported cases represent only 10% of actual cases meeting the CDC current surveillance criteria.

For rally information see [www.LymeRights.org](http://www.LymeRights.org)

For information on Lyme disease, see [www.LymeDiseaseAssociation.org](http://www.LymeDiseaseAssociation.org)

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