

# Institute of Med.: Lyme Wrkshp Rept.

The Institute of Medicine (IOM) released its Critical Needs and Gaps in Understanding Prevention, Amelioration, and Resolution of Lyme and Other Tick-Borne Diseases: The Short-Term and Long-Term Outcomes Workshop Report, on April 20, 2011.

In a move designed to protest the National Institutes of Health's (NIH) use of the IOM to conduct a workshop NIH was charged with organizing, the Lyme Disease Association (LDA), Time for Lyme (TFL), and the California Lyme Disease Association (CALDA), pulled out of the IOM workshop process and did not submit their commissioned scientific paper to the IOM committee. The three groups raised strong objections to the IOM process which:

1. permitted bias on the workshop committee and lack of transparency.
2. failed to satisfy the intent or objectives as delineated in Congressional Appropriations language.

On September 29, 2010, Congressman Christopher Smith (NJ) introduced for inclusion in the Congressional Record, "The Patient Perspectives on the Research Gaps in Tick Borne Diseases," which he stated was written by "three of the Nation's largest Lyme disease advocacy organizations [LDA, CALDA, TFL], who represent tens of thousands of patients."

Links are provided below to review the IOM workshop proceedings, Lyme group actions, the Congressional report and the IOM workshop report.

[September 20, 2010 Lyme Disease Association Press Release- Non Compliance Causes Lyme Patient Groups to Withdraw from Scientific Meeting](#)

September 29, 2010 Congressional Record 111th Congress Report-  
“The Patient Perspectives on the Research Gaps in Tick Borne  
Diseases”.

<http://thomas.loc.gov/cgi-bin/query/z?r111:E29SE0-0367:>

October 5, 2010 Lyme Disease Association Press Release-  
[Research Gaps in Lyme Disease Exposed in the Congressional  
Record](#)

April 20, 2011 IOM Workshop Report

[http://www.nap.edu/catalog.php?record\\_id=13134](http://www.nap.edu/catalog.php?record_id=13134)

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## **Petition: Grps' Withdraw from IOM Forum**

Sign up here! Let Congress know you support decision by LDA, TFL and CALDA to withdraw from the Institute Of Medicine's (IOM) State-of-the-Science Lyme and Tick-Borne Disease Workshop.

Please let Congress know you support the move by LDA, TFL and CALDA to withdraw from the NIH/IOM State-of-the-Science Lyme Disease and Other Tick Borne Diseases Workshop by reading the statement below and completing the response form. LDA will send your reply directly to Congressman Christopher H. Smith (NJ). It will not be used for any purpose other than this project. Thank you!

**Lyme Groups Withdraw from Scientific Meeting**

I support the move by the national Lyme Disease Association

(LDA), the California Lyme Disease Association (CALDA), and Time For Lyme (TFL) to withdraw from the National Institutes of Health (NIH) sponsored workshop. I agree that the above groups should not participate in nor submit the Institutes of Medicine's (IOM) commissioned scientific paper to the Panel in protest of the IOM's workshop about the state of the science regarding Lyme and tick-borne diseases. Despite the 3 groups' repeated requests for transparency and a balance of scientific viewpoints, as delineated in Congressional Appropriations language, neither the hearing panel nor the speakers selected by the IOM satisfy the Congressional intent or objectives.

The IOM's mission was to provide an "independent, objective and non-partisan" program and there are no scheduled speakers with opposing viewpoints of similar scientific weight to balance Infectious Diseases Society of America (IDSA) presentations about the research gaps in Lyme disease. Many state-of-the-art scientific researchers, experienced clinicians and patient advocates have been relegated by the IOM and NIH to spectator positions. I believe that this amount of bias undermines the integrity of the scientific workshop and that its final report will reflect this lack of objectivity.

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For more information

[Lyme Groups Press Release](#)

[Institute of Medicine \(IOM\) Lyme and other tick-borne diseases workshop meeting description](#)

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# Non Compliance Causes Lyme Patient Groups to Withdraw from Scientific Meeting

In a move designed to protest the Institute of Medicine's upcoming Lyme disease workshop, three of the nation's largest and most influential Lyme groups have pulled out of the process.

## **NIH Does Not Comply with Congressional Appropriations Language Lyme Patient Groups Compelled to Withdraw from Scientific Meeting**

**September 20, 2010** – In a move designed to protest the Institute of Medicine's upcoming Lyme disease workshop, three of the nation's largest and most influential Lyme groups have pulled out of the process. After much deliberation, speaker Diane Blanchard, co-president of the Time for Lyme (TFL- CT) has withdrawn from the panel. The national Lyme Disease Association (LDA- NJ) and the California Lyme Disease Association (CALDA), along with TFL, will not participate in the workshop and their IOM commissioned scientific paper will not be submitted.

The scientific workshop was promoted by the Institute of Medicine (IOM) to be a conference about the state of the science regarding Lyme and tick-borne diseases. Despite the groups request for transparency and a balance of scientific viewpoints, as delineated in Congressional Appropriations language, neither the hearing panel nor the speakers selected by the IOM satisfy the Congressional intent or objectives.

The IOM's mission was to provide "independent, objective and non-partisan" advice to policy makers, yet the majority of the participants sitting on its Lyme disease panel belong to the Infectious Diseases Society of America (IDSA), a medical society with a known bias. Many key speaker roles were given to physicians who are IDSA

members and supporters, a number of whom were involved with the IDSA's controversial guidelines for Lyme. IDSA's Lyme guideline development process was investigated by the Connecticut Attorney General which resulted in exposing the guideline panel as being riddled with undisclosed conflicts of interest.

In spite of the recommendations to NIH by Congress, the conference opens with perhaps the most polarizing figure in the chronic Lyme debate— Dr. Gary Wormser of Westchester Medical Center – who chaired the IDSA Lyme guideline panel and whose highly controversial biased views are well known. There are no scheduled speakers with opposing viewpoints of similar scientific weight to balance his presentation about the research gaps in Lyme disease. Many state-of-the-art scientific researchers and experienced clinicians have been relegated by the IOM and NIH to simply spectator positions.

The patient-oriented Lyme groups believe that this amount of bias undermines the integrity of the scientific workshop and that its final report will reflect this lack of objectivity. “We believe the entire process has the potential to cause additional harm to patients. After much deliberation our only recourse is to withdraw our support for this seriously flawed process. From the inception, TFL, LDA and CALDA have communicated our concerns, which were ignored. We remain hopeful that NIH/IOM will revamp the program to comply with the Congressional language which was responsible for initiating the workshop,” the groups said in a joint statement.

Time for Lyme, [www.timeforlyme.org](http://www.timeforlyme.org), the national Lyme Disease Association, [www.LymeDiseaseAssociation.org](http://www.LymeDiseaseAssociation.org), and California Lyme Disease Association, [www.lymedisease.org](http://www.lymedisease.org), are non-profit organizations that were founded by individuals who had personal experience with Lyme disease, in order to address the lack of research, education and support services available for this emerging infection.

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# **Institute of Medicine Review**

**of Lyme**