

## **House Passes Lyme Bill**

The Lyme Disease Association, Inc., LDA, is pleased to announce that the Lyme bill, HR 4701 - "Vector-Borne Disease Research Accountability and Transparency Act of 2014" as amended, was discussed on the floor of the U.S. House of Representatives today, September 9, and passed the House by voice vote.

"This legislation is truly constituent-driven and represents a significant step forward in what has been an extensive process," said Congressman Gibson. "For the past few years, I have worked with physicians, patient advocates, professional researchers, patients and their families throughout New York and the United States on a bill that focuses solutions. I want to thank Pat Smith and other Lyme advocate leaders for their significant and persuasive engagement and unyielding commitment to change the direction of U.S. policy to bring solutions and relief for our chronic sufferers. This bill is dedicated to those patients who have been ill for years, at times seemingly without hope, wondering if anyone in Washington was listening or cared. We hear you. We do care, and today we passed this legislation to help you get better."



*Representative Chris  
Gibson*

The bill sets up a working group with patients and physicians at the table and contains language requiring the Secretary of HHS to submit a strategic plan to Congress to include "a plan for improving outcomes of Lyme disease and other tick-borne diseases, including progress related to chronic or persistent symptoms and chronic or persistent infection and co-infections; ... a plan for improving diagnosis, treatment, and prevention."

The bill also specifies that the Working Group established shall meet at least twice each year and that it shall be subject to the Federal Advisory Committee Act (FACA), which requires transparency in operations of the Working Group. Under FACA, meetings must be publicly announced, open, and provide an opportunity for divergent viewpoints. Minutes, as well as other records and reports must be made available to the public. FACA also stresses the importance of having a fairly balanced membership in terms of points of view represented.

"This bill provides Lyme patients with a much needed voice in the shaping of public policy in Washington, DC, in a transparent setting. All aspects of the Lyme disease question including, chronic Lyme, will be examined, with participants of differing viewpoints coming together in discussion with the same goal in mind, finding research pathways which will help find a cure for Lyme disease and prevent new cases of all tick-borne diseases," said Lyme Disease Association President, Pat Smith.

The LDA led a nationwide campaign to support this patient protective legislation and organized a letter signed by 154 Lyme & tick-borne disease groups and others that was sent to all members of the House Energy & Commerce Committee.

The LDA thanks Representative C. Gibson (NY), bill sponsor; original co-sponsors C. Smith (NJ), Courtney, Peterson, Wolf, Barletta; and other bill sponsors and Representatives who supported the bill; the Energy and Commerce Committee; and leadership of the House. Also, we appreciate the favorable remarks about the bill on the floor after Mr. Gibson spoke, from Mr. Maloney of NY, and Mr. Smith of NJ.

We also thank our partner groups nationwide who were instrumental in the effort to pass this legislation, and all Lyme groups across the country, patients, and other groups who worked on this effort. The next step for the bill is to go to the Senate, where we hope it will be given prompt consideration.