

# Update on Federal Lyme & Tick Borne Disease Legislation

Office of Congressman Chris Gibson  
Dutchess County Tick Task Force & Senator Sue Serino  
Tick Information Meeting  
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Wallace Center, Hyde Park, NY

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## **H.R. 6 - 21 Century Cures Act**

**Bill Summary:** To accelerate the discovery, development, and delivery of 21st century cures, and for other purposes

### **SECTION 4061 - LYME DISEASE AND OTHER TICK-BORNE DISEASES SUMMARY**

- \* This section would help to accelerate improved methods for prevention, diagnosis, and treatment of Lyme disease.
- \* It would establish a working group to prepare a report that would summarize federal research efforts related to Lyme disease and other tick-borne diseases.
- \* Informed by the report prepared by the working group, the Secretary would develop a strategic plan to improve health outcomes.

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## **H.R. 6 - 21 Century Cures Act Status**

- \* Section 4061, Part W is essentially the same language that Congressman Gibson authored in H.R. 4701, the "Tick-Borne Disease Research Accountability and Transparency Act of 2014".
- \* H.R. 4701 - Passed House of Representatives September 9, 2014.
- \* H.R. 6 - Passed House of Representatives July 10, 2015. Vote was 344-77.

## **H.R. 6: PART W - LYME DISEASE AND OTHER TICK-BORNE DISEASES**

### **SEC. 3990O. RESEARCH.**

"(a) IN GENERAL.—The Secretary shall conduct or support epidemiological, basic, translational, and clinical research regarding Lyme disease and other tick-borne diseases.

"(b) BIENNIAL REPORTS.—The Secretary shall ensure that each biennial report under section 403 includes information on actions undertaken by the National Institutes of Health to carry out subsection (a) with respect to Lyme disease and other tick-borne diseases, including an assessment of the progress made in improving the outcomes of Lyme disease and such other tick-borne diseases.

## **H.R. 6: PART W - LYME DISEASE AND OTHER TICK-BORNE DISEASES**

### **SEC. 3990O–1. WORKING GROUP.**

"(a) ESTABLISHMENT.—The Secretary shall establish a permanent working group, to be known as the Interagency Lyme and Tick-Borne Disease Working Group, to review all efforts within the Department of Health and Human Services concerning Lyme disease and other tick-borne diseases to ensure interagency coordination, minimize overlap, and examine research priorities.

### **Working Group Responsibilities**

#### **The Working Group shall—**

"(1) not later than 24 months after the date of enactment of this part, and every 24 months thereafter, develop or update a summary of—

"(A) ongoing Lyme disease and other tick-borne disease research related to causes, prevention, treatment, surveillance, diagnosis, diagnostics, duration of illness, intervention, and access to services and supports for individuals with Lyme disease or other tick-borne diseases;

"(B) advances made pursuant to such research;

"(C) the engagement of the Department of Health and Human Services with persons that participate at the public meetings required by paragraph (5); and

### **Working Group Responsibilities (Continued)**

“(D) the comments received by the Working Group at such public meetings and the Secretary’s response to such comments;

“(2) ensure that a broad spectrum of scientific viewpoints is represented in each such summary;

“(3) monitor Federal activities with respect to Lyme disease and other tick-borne diseases;

“(4) make recommendations to the Secretary regarding any appropriate changes to such activities; and

“(5) ensure public input by holding annual public meetings that address scientific advances, research questions, surveillance activities, and emerging strains in species of pathogenic organisms

### **Working Group Membership**

“(1) **IN GENERAL.**—The Working Group shall be composed of a total of 14 members as follows:

“(A) **FEDERAL MEMBERS.**—Seven Federal members, consisting of one or more representatives of each of—

“(i) the Office of the Assistant Secretary for Health;

“(ii) the Food and Drug Administration;

“(iii) the Centers for Disease Control and Prevention;

“(iv) the National Institutes of Health; and

“(v) such other agencies and offices of the Department of Health and Human Services as the Secretary determines appropriate.

### **Working Group Membership (Continued)**

“(B) **NON-FEDERAL PUBLIC MEMBERS.**—Seven non-Federal public members, consisting of representatives of the following categories:

“(i) Physicians and other medical providers with experience in diagnosing and treating Lyme disease and other tick-borne diseases.

“(ii) Scientists or researchers with expertise.

“(iii) Patients and their family members.

“(iv) Nonprofit organizations that advocate for patients with respect to Lyme disease and other tick-borne diseases.

“(v) Other individuals whose expertise is determined by the Secretary to be beneficial to the functioning of the Working Group.

### **Working Group Appointment**

The members of the Working Group shall be appointed by the Secretary, except that of the non-Federal public members under paragraph (1)(B)—

“(A) one shall be appointed by the Speaker of the House of Representatives; and

“(B) one shall be appointed by the majority leader of the Senate.

“(3) **DIVERSITY OF SCIENTIFIC PERSPECTIVES.**—In making appointments under paragraph (2), the Secretary, the Speaker of the House of Representatives, and the majority leader of the Senate shall ensure that the non-Federal public members of the Working Group represent a diversity of scientific perspectives.

“(4) **TERMS.**—The non-Federal public members of the Working Group shall each be appointed to serve a 4-year term and may be reappointed at the end of such term.

### **Working Group Reporting**

Not later than 24 months after the date of enactment of this part, and every 24 months thereafter, the Working Group—

“(1) shall submit a report on its activities, including an up-to-date summary under subsection (b)(1) and any recommendations under subsection (b)(4), to the Secretary, the Committee on Energy and Commerce of the House of Representatives, and the Committee on Health, Education, Labor, and Pensions of the Senate;

“(2) shall make each such report publicly available on the website of the Department of Health and Human Services; and

“(3) shall allow any member of the Working Group to include in any such report minority views.

### **H.R. 6: Part W: Strategic Plan**

“Not later than 3 years after the date of enactment of this section, and every 5 years thereafter, the Secretary shall submit to the Congress a strategic plan, informed by the most recent summary, for the conduct and support of Lyme disease and tick-borne disease research, including—

“(1) proposed budgetary requirements;

“(2) 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;

### **H.R. 6: Part W: Strategic Plan**

“(3) a plan for improving diagnosis, treatment, and prevention;

“(4) appropriate benchmarks to measure progress on achieving the improvements described in paragraphs (2) and (3); and

“(5) a plan to disseminate each summary and other relevant information developed by the Working Group to the public, including health care providers, public health departments, and other relevant medical groups.”.

Senate Lyme & Tick Borne Disease Legislation

S. 1503 : Lyme and Tick-Borne Disease Prevention, Education, and Research Act of 2015

To provide for enhanced Federal efforts concerning the prevention, education, treatment, and research activities related to Lyme disease and other tick-borne diseases, including the establishment of a Tick-Borne Diseases Advisory Committee

### **S. 1503 : Lyme and Tick-Borne Disease Prevention, Education, and Research Act of 2015 - Status**

\* Introduced by Senator Blumenthal June 4, 2015.

\* Referred to the Senate Committee on Health, Education, Labor, and Pensions.

\* Currently 17 Co-Sponsors in the Senate, including Senators Gillibrand and Schumer.

\* Trying to get this language included in a Senate Health Bill before July, 2016.

### **S. 1503 Bill Summary**

#### **Lyme and Tick-Borne Disease Prevention, Education, and Research Act of 2015**

This bill requires the Department of Health and Human Services (HHS) to establish the Tick-Borne Diseases Advisory Committee to advise HHS on how to:

(1) ensure coordination with other federal agencies, private organizations, and constituency groups regarding efforts to address Lyme disease and other tick-borne diseases;

(2) ensure that a broad spectrum of scientific viewpoints is considered in public health policy decisions and that information disseminated to the public and physicians is based on the best available science;

(3) advise federal agencies on priorities related to tick-borne diseases.

### **S. 1503 Bill Summary**

HHS must coordinate federal activities related to tick-borne diseases and conduct or support activities related to tick-borne diseases, including:

\* developing diagnostic tools and tests,

\* improving the efficient utilization of diagnostic tests,

\* surveillance and reporting,

\* providing and promoting access to a clearinghouse of information,

\* increasing public education,

### **S. 1503 Bill Summary (Continued)**

\* creating a physician education program on the latest research and treatment options for Lyme disease,

\* research on tick repellents and strategies for the control of ticks,

\* exploring the potential for vaccines,

\* establishing epidemiological research objectives, and

\* determining the effectiveness of different treatments.

### **Moving Forward**

- \* Best opportunity for success is for Senate to include S. 1503 language in a Senate Health Bill in next 8 weeks.
- \* From there, House and Senate will go to Conference Committee to work out final version/language to be included in final legislation. Once that passes both chambers, it goes to the President for final signature.
- \* If the Senate does not include Lyme language in any bills, there is a chance that the House language can be included in the Conference Committee report.

**Thank You!**

**For more information, contact:**

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