

# Big news for Lyme disease sufferers

House passes breakthrough legislation on issue

## Lyme

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A sign warns of ticks in the area.

THINKSTOCK

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For decades, Wall resident Pat Smith has implored the medical establishment to acknowledge the existence of chronic Lyme disease. On Wednesday, her quest took a big step forward.

The U.S. House of Representatives passed the 21st Century Cures Act, a comprehensive health care bill that would establish a national working group on Lyme disease. The 14-member panel would include physicians with experience in treating tick-borne diseases, Lyme patients and advocates for those suffering from the condition.

"This is really groundbreaking," said Smith, president of national nonprofit Lyme Disease Association in Wall. "Prior to this we've never had anything at the federal level that permitted patients to be at the table with federal officials. It's desperately needed."

Lyme disease affects nearly 400,000 people per year in the U.S., most of whom live in the northeast. For many who are diagnosed promptly, the standard month-long course of antibiotics miti-



U.S. Rep. Chris Smith

BOB BIELK/STAFF PHOTOGRAPHER

gates the illness. But detection is difficult, and for thousands of folks, the symptoms continue for months or years.

To date, the influential Infectious Diseases Society of America has declined to recognize chronic Lyme in its clinical practice guidelines. Chronic Lyme advocates say that omission has caused a domino effect of needless suffering.

U.S. Rep. Chris Smith, R-New Jersey, has been pushing for a federal panel to address the issue since the early 1990s. The Senate is expected to pass the Cures Act, which got through the House by a vote of 392-26, in the coming days.

"Many have suffered for decades with this debilitating disease, only to be told that their illness does not exist," Chris Smith said in a statement. "Enactment of the Cures package will move us one step closer to acknowledging and addressing the root problems of chronic Lyme."

The issue was first brought to Rep. Smith's attention by Pat Smith. In the late 1980s Lyme disease afflicted two of her daughters, one of whom missed four years of school. For years, she and Chris Smith (no relation) worked in vain to get federal recognition of chronic Lyme.

"The continued dissemination of outdated guidelines... has contributed to medical community's denial of chronic Lyme disease and the denial of coverage by insurance companies of treatments for chronic Lyme disease," Rep. Smith told the Asbury Park Press in a wide-ranging interview on the subject in May.

New Jersey ranks second among all states in Lyme cases, with 4,855 reported in 2015. Since the condition is known to be under-reported because it can be difficult to detect, the actual number of cases in the Garden State is believed to be closer to 50,000.

"Having knowledgeable people at the table will put the focus on the research, and there is a huge amount of brand-new research that shows there are (Lyme) cells that are left over after regular treatment," said Pat Smith, who was involved in drafting the language establishing the working group. "This may be the root of the problem."

In addition, she said, the Cures Act "will cause these federal agencies to have to talk about all of this in public."

For both Pat and Chris Smith, it marks a victory after prior attempts to create a national task force were rejected.

"My original legislation ensured the individuals impacted by federal policies would have a seat at the table when the decisions are made," Rep. Smith said. "It has taken many years and several drafts, but thankfully today's Cures package includes similar language that will begin the process of addressing the great unmet needs in the Lyme community in an open and transparent manner."

For more information on the Wall-based Lyme Disease Association, visit [www.lymediseaseassociation.org](http://www.lymediseaseassociation.org).

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