

Govt Agencies Deny Persistent Lyme at WG: Take Action Now!



ACTION Recommended by LDA: Make Your Voices Heard on Persistent Lyme to the Working Group Now! **June 24th Deadline.**

Our government denies persistent (chronic) Lyme and refuses to acknowledge and help those patients. Please submit comments, can be short, about the existence and importance of persistent (chronic) Lyme. How it affects your life, family, job, school, and your doctors. Only your action by June 24th can make them listen!

- **Submit Comments** (verbal or written) for the next meeting by Wednesday, June 24th
- **Next Meeting** held online, Wednesday July 8th
- **Register** for the online meeting
- **View Agenda**

View Lyme controversy on videos below!

History of Working Group (WG) Formation:

The 21st Century Cures Act, signed into law in 2016, called for the formation of a 14-member Tick-Borne Disease Working Group, to work under the auspices of the US Department of Health and Human Services (HHS). The panel would bring together

representatives of various federal agencies, medical experts, scientists, and Lyme disease patient advocates. Together, they would strategize the best ways for the government to combat the huge public health threat posed by acute Lyme, persistent Lyme, symptoms, and other tick-borne diseases. Giving patients a voice in policy decisions that deeply affect them was an issue long championed by the Lyme community.

First Term of the Working Group – Success:

The Working Group was set up to last six years, reporting to Congress about its progress every two years. The first iteration of the panel, named in 2017, included three representatives of Lyme patients. The Working Group's Report to Congress was submitted at the end of 2018, with generally good reviews from the Lyme community. It appeared progress was being made.

Current Term of the Working Group – Controversy:

Only one patient advocate chosen... Things took a different turn in 2019, with the naming of the next panel. There was obfuscation, lack of transparency, and process irregularities from the very start. The Working Group's membership wasn't even publicly announced until less than a day before its first meeting on June 4. Only one patient advocate was chosen—LDA President Pat Smith. And, in a move that especially stuck in the craws of Lyme patients everywhere, the IDSA's Dr. Eugene Shapiro was appointed as well.

Controversial IDSA doctor chosen for Working Group... Dr. Shapiro is well-known for publicly mocking and belittling Lyme patients and their concerns, and for helping target the medical licenses of Lyme-treating doctors who don't follow the IDSA's Lyme guidelines, which he co-authored. He also has flagrant Lyme-related financial conflicts of interest that should have precluded him from serving on the Working Group according to the opinions of many people. (More than 38,000 people have signed a petition to remove Shapiro from the panel (see petition). Despite many inquiries, there has been no

official response from HHS regarding the petition.)

Co-Chair announces enough focus on Lyme, must focus on other tick-borne diseases... Also at that opening meeting on June 4, newly appointed co-chair David Walker MD—who is an expert in rickettsial infections, not Lyme disease—made a startling announcement. He said that the prior Working Group had spent enough effort on Lyme disease, and he thought the new group should put its energies elsewhere.

(Note: According to the CDC, 82% of the cases of tick-borne infection in the US are Lyme disease. Shouldn't it get 82% of the group's attention? Furthermore, the first panel was aware there were still many Lyme related issues to be further explored.)

Non-Attendee Votes by Proxy... For example, at a two-day meeting in Philadelphia on March 3 and 4, Eugene Shapiro did not attend in person nor did he participate by telephone. However, when it came time to vote, Co-chair Walker cast votes on his behalf. Pat Smith questioned this and was basically told, "We checked. It's allowed." (Wait...what? Why have any debate at all if an absent panelist can pre-program his votes in advance?)

Agencies refuse to address persistent Lyme (Pat Smith strongly responds – see 2.5 min. video below)... Also at that meeting, discussions edged closer to the controversial "elephant in the room"—the topic of persistent Lyme disease and the failure of US health agencies to adequately address it. Pat Smith pointed out that the CDC website only acknowledges acute Lyme disease. She said this leaves people who remain sick after beyond the early stages of the illness—along with their doctors—without any advice at all. In response, CDC spokesperson Ben Beard insisted, "The vast majority of Lyme disease patients are served quite well by the guidance we have on our website." After representatives of several agencies echoed similar responses, ***here's how Pat replied:***

(Clip 2.5 min.)

(NOTE: Once viewed, hit your browser's refresh button to view again)

Dennis Dixon, NIH, Ben Beard CDC, and Pat Smith responding:

The segment is about unsettled science, 2 guidelines, Lyme 2 different diseases, Lyme only in certain states...

(Clip 13 min.)

(NOTE: Once viewed, hit your browser's refresh button to view again)

Pat Smith asking CDC are there 2 Standards of Care – CDC Replies No

(1 min.)

(NOTE: Once viewed, hit your browser's refresh button to view again)

Controversy continues at April 27th meeting... The following month, the contentious issue of persistent Lyme disease again reared its head during April 27's online audio meeting.

Below shows the agencies refusal to acknowledge persistent Lyme disease and need for treatment guidelines.

- A subcommittee put forth the following recommendation for a vote: **Recommend that IF the CDC posts any Lyme treatment guidelines, that they include guidelines on persistent Lyme disease.** Unexpectedly, five panelists abstained—which left five yes votes and 3 no votes. (One member was absent.)
- Remarks made after the vote seemed to indicate that the abstainers felt they had defeated the measure, because “yes” votes didn't comprise a majority of panel members.

But the Working Group found out abstentions don't effect outcome of the yes or no total. So, the recommendation passed, 5-3.

- At that point, one of the abstainers announced that he wanted to change his vote to "no." That request was denied. There was heated discussion about whether the panel could or should hold a re-vote on the matter. After a lot of back and forth discussion, two motions were made and seconded, one was withdrawn, and the second ended with a vote on whether to have a revote. That vote resulted in not overturning the original vote. The recommendation in the first bullet above stands.

Other Working Group Information:

Lyme Disease Association (LDA) Working Group Page

Health & Human Services (HHS) Working Group Page

LDo, TOUCHED BY LYME: Persistent Lyme a sticking point for TBD Working Group

Lyme Disease Association, Inc. thanks all the advocates who contributed to this page, especially Dorothy Leland.

The videos provided in the article are segments from the official Working Group meeting videos.