

LDA Pres: Last Remarks to Working Group on Suppression of Chronic Lyme



LDA Pres.
Patricia Smith

On her last day as an HHS Working Group (WG) member, after serving 2 terms, Lyme Disease Association President Pat Smith addressed at the Dec. 2 online WG meeting, her concerns about the procedures of the 2019-2020 Working Group and her concern that the interests of patients were not served by the group. Read below or listen to her audio comments ([LINK](#))

Pat Smith's written closing words to WG on Dec. 2, 2020 (actual verbal may have varied slightly)

THANKS WG 1: Since this is the last WG meeting for me, I first want to thank the entire 2018-19 Working Group I served on including staff and subcommittees. Working together, WG 1 produced a powerful report which incorporated the issues that were important to patients. Congratulations for that achievement. I was excited for progress for patients who had hope for the future.

THANKS WG 2: Now I want to thank public commenters & Jim & Kaye and all the current **subcommittee** members who worked so hard to lay groundwork for the backbone of the 2020 WG report and those current Working Group members who demonstrated their

commitment to supporting long suffering chronic Lyme patients. I especially thank my Chapter Co-Chair, Captain Scott Cooper, an advanced practice provider from CMS, who worked tirelessly and selflessly to help patients.

PROBLEMS: Unfortunately, and I would be hypocritical if I said otherwise, despite these efforts, this report will do little to help patients. It was flawed from the onset; the WG member selection was cloaked in secrecy, about who they were. If we did find out, we were not permitted to release names. When IDSA unilaterally publicly announced the appointment of Eugene Shapiro to the WG, speculation was rampant as to **who was really in charge** of this WG. The handwriting was on the wall. It was no surprise when Dr. Shapiro, an author on the last IDSA guidelines, was permitted, without WG discussion or knowledge, except by Chairman Walker, to give his proxy vote to Walker, when he missed meetings, thus violating the concept of having members with diverse viewpoints sitting at the same time, same meeting, in public under FACA, having discussions to reach consensus on a report to Congress.

Since Meeting 1, when Chairman Walker, a *Rickettsia* expert, announced that Lyme had already been done by the first WG, and this WG would do a brief update on Lyme and concentrate on other TBDs, it was clear the patient interests would be targeted. Each meeting the patient chapter was rigorously scrutinized and held to a different standard than the other chapters.

Attempts were first made behind the scenes to allow anyone to write a minority report before any consensus vote was taken, although through a vote, the majority of the WG did not allow that to happen. 2 weeks ago, the tenor of the report discussion changed to an entire rewrite of our chapter, devolving into a real "food fight." A motion to keep the Chapter as it was, passed 8-6. 3 minority reports have been produced for that chapter, including the 3 government agencies objections, CDC, NIH, FDA.

WHO'S IN CONTROL: The government agencies have been forced to take a public stand against the Patient Chapter, dismissing chronic Lyme disease and continuing the denial of treatment to sick Lyme patients, alongside their partners in a powerful medical society, one whose new Lyme guidelines were just released two days ago. Their public talk has centered on what is good for the patient, but their decisions do not reflect that sentiment. The question thus becomes, whose interest was this panel designed to serve: those of the patients who for two decades fought to pass the enabling legislation for this panel to help focus on their plight, chronic Lyme disease, or for medical specialty society special interests.

LYME IS MARGINALIZED: Other diseases are treated seriously. HIV researchers developed a gold standard test within a few years, Lyme still has none. Leprosy has had more clinical trials than Lyme disease, which ranks 14th out of 15 diseases in infectious diseases trials. Within 9 months, COVID 19 had several treatments, tests and upcoming vaccines. To the Lyme patients, I am so sorry you have been again marginalized by those charged with your health, but we gratefully thank any current Working Group members who worked hard to provide the help you so desperately need.

I leave you all with a quote from the late Issac Asimov, noted author:

“Your assumptions are your windows on the world. Scrub them off every once in a while or the light won't shine in.”

These windows haven't been scrubbed in almost 46 years. Thank you.

Read more about WG from LDA:

11th Hour Attempt to Commandeer & Rewrite Patient Chapter Fails

Working Group Meeting: Lyme Patient Access to Care Still Under Attack

Contentious Working Group Meeting Vote on CDC Posting Lyme Guidelines

TBDWG Mtg 12: Training, Education, Patient Access to Care (Video)

Contentious 9 Hour WG Meeting: Persistent Infection a Religious Belief? WG Co-Chair Says Yes

Click to listen to Pat Smith's Final Remarks to the TBDWG: