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

The recent 2-day virtual meeting of the Federal Tick-Borne Disease Working Group (WG) on Day 1 was more subdued than prior meetings, but Day 2 again brought forth an effort to minimize the patient access to care chapter and chronic Lyme.

Day 1 September 15, 2020

Patients and patient advocates delivered verbal comments, including advocate Carl Tuttle, who asked Pat Smith “to hold Shapiro’s feet to the fire” in regard to persistent Lyme and patient advocate Lucy Barnes, who stated “patients are fighting for their lives” and “you know better.” Erin Walker, wife of PGA tour winner Jimmy Walker, a Lyme patient, emphatically expressed the need for better testing and better treatment as Lyme is a “real disease that affects real Americans.” Problems with patient access to care was a common theme in the verbal comments.

WG member Angel Davey presented a report from the Public Comments Subcommittee, which summarizes incoming public comments: priority areas/key themes. Of note were the number of comments received in June and July 2020 after the June 8th meeting of the WG. Recurrent themes of these comments included

- “Denying the existence of persistent or chronic Lyme disease…”
- “Access to care is poor…”
- “Sero logic diagnostic testing and CDC guidelines are
Persistent/chronic Lyme disease symptoms cited include: musculoskeletal pain, cramps, twitches, bladder pain, severe/chronic fatigue, swollen joints, arthritis, heart arrhythmias, mental illness, insomnia, Bell’s palsy, numbness, foot drop, inflammation, food allergies, digestive issues, skin issues, light/noise/tactile sensitivities

“Lyme disease misdiagnosis is rampant...”

The final July slide states

“Patients with chronic Lyme & other TBDs are being failed by the healthcare system”

“Patients with chronic Lyme must be heard”

“Deniers of chronic Lyme disease need to be removed from the TBDWG”

Chapter 8: Epidemiology and Surveillance Review.
In the discussion of this chapter, Pat Smith again reiterates that recommendations posted on the CDC guidelines webpage only addresses acute Lyme, and that this is the only guidance available to physicians and patients seeking resources. This chapter contains the minority report addressing “Effect of Geographic Restrictions on Lyme Diagnosis,” which specifies why the “diagnosis by geography” proviso should not have been removed from the WG report as a recommendation to Congress. The original recommendation which was in the patient access chapter was “CDC provide input to the Council of State &
Territorial Epidemiologists, CSTE, that the Lyme disease surveillance case definition be revised such that it abandons the use of geographic parameters for the diagnosis of Lyme disease and inform clinicians and the public that Lyme disease has been reported in all states.”

On the topic of non-tick-bite transmission, Pat vehemently disagreed with Sam Donta that modes such as “other insect vectors” be dropped from discussion stating that more research is needed on possible insect-borne transmission, since research has shown mosquitoes can carry the Lyme bacteria, and that “the whole process has been subverted to begin with.”

Chapter 9: Looking Forward Review: where Eugene Shapiro continued to contest the use of “persistent Lyme disease”. Repeated comments in the side bars viewable to the public included “persistent Lyme disease is undefined and is not a scientifically defined or recognized entity.”

Day 1 concluded with reviews of Chapters 1: “Background,” Chapter 2: “Methods,” and the Table of Contents and Title Page. Further review of the suggestions will be considered at another meeting.

After a lengthy discussion, a decision was made to include a separate chapter in the report to congress on Public Comments.

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Day 2-September 22, 2020
Day 2 of meeting 15 resumed Sept. 22, beginning with reviews of Chapter 3: “Tick Biology, Ecology, and Control,” presented by CDC’s Dr. Ben Beard. Of note was that two times as many TBDs have been discovered in the past 60 years than the previous 60 years.

Chapter 4: Clinical Manifestations, Diagnosis, and Diagnostic Review: was presented by Dr. Sam Donta. Immediately, there was a replay of the June 8 meeting with further disagreement
regarding the word “likely” versus “possibly.” Dr. David Walker stated “likely as too strong a word” regarding the hypothesis that the effects of persisting organisms are the source of ongoing symptoms in patients with unresolved Lyme disease. After much discussion and disagreement regarding persistence, the WG agreed that a statement such as “Evidence continues to be gathered that supports that persistent infection plays a role” may be an acceptable solution, and wording will be revisited by the co-leads of this chapter.

Convergent views and difference of opinion continued into Chapter 5 review: “Causes, Pathogenesis, and Pathophysiological,” where disagreements arose about TBD ability to suppress, subvert or modulate immune system in humans and effects to response to treatment and increase risk of developing other infections. Dr. Walker stated that “this speculation requires a reference. I do not know of any supportive evidence.” Although Angel Davey cited references on human effects, arguments over the validity of animal studies to translate to human effects continued. It was agreed that further studies are needed.

Chapter 6: Treatment Options and Strategies Review: was presented by Dr. Sam Donta and Dennis Dixon, NIH. When discussing Rickettsial diseases, Pat Smith requested that the stated fatality rate of 20% be cited and/or updated with current numbers. Dr. Walker argued that this statement was in regard to untreated infections, however Pat argued that these numbers are being quoted from 1940’s and 1950’s studies, and that current citations are needed. Ben agreed to update with more timely and relevant data, especially bringing forth regional outbreaks in Arizona, which have higher numbers. Pat then said great, we can then include numbers from Lyme in high case areas.

Chapter 7: Clinician and Public Education, Patient Access to Care Review: was presented by Pat Smith and captain Scott Cooper, PA, the latter went down the previously addressed
(online) comments one by one explaining the changes he and Ms. Smith had made. Drs. David Walker and Eugene Shapiro surfaced on the topic of “persistent Lyme.” This chapter review was again the longest and most contentious of all chapters discussed. Walker started off by disputing the patient percentage numbers that describe chronic and often debilitating symptoms. He believes the cited 35% to be too high and inconsistent with numbers used previously in the report. Walker’s comments on the sidebar of the report continue to argue that “persistent/chronic Lyme disease is an unproven hypothesis, and accused Pat Smith of using this chapter to address “the author’s pet topics.” She explained that these numbers were generated from a study conducted by Dr. John Aucott, Johns Hopkins University. Shapiro went on to discredit the Aucott study arguing the validity of the patient cohort, to which Smith responded that the patient cohort was comprised of all EM rash patients. Ultimately, it was agreed that Captain Cooper and Ms. Smith would revise and include a range of percentages from various Lyme patient studies with chronic or persistent symptoms.

However, Shapiro continued his attack of the topic of “persistent Lyme disease” while attempting to discredit the use of the largest patient registry, MyLymeData with comments written on the sidebar of the report stating “This is mostly propaganda and typically based on self-reports with no confirmation that the patients have Lyme disease.” In regard to the data presented where “67% (of patients) report that they have postponed or avoided medical treatment due to discrimination, disrespect or difficulty obtaining care, and nearly half (47%) report that they have been denied treatment.” Shapiro argued the credibility of the patient registry responding to Pat Smith, “I don’t buy it.” She explained that NIH uses patient registries, 72 of them. Pat went on to describe that this patient registry is a rigorous one, featured in college textbooks, in collaboration with UCLA, and a registry that has resulted in citations in 4 peer
reviewed studies as well as having received $800,000 in funding from the National Science Foundation. Walker argued that “the evidence isn’t there that it really is associated with Lyme disease.” Dennis Dixon suggested a writing a preamble to this section describing what patient registries are and how they are collected. Pat responded, “we can certainly do that, but I believe that again, we are being discriminated against…our patients…and all of the information we have about them.” She further explained “every time we present something that other people use with many, many other diseases, it’s like we have to jump through hoops in order to indicate these people are sick.”

In response to erroneously reported case numbers that were discovered in the past subcommittee report on ehrlichiosis/anaplasmosis, Smith and Cooper replaced report text with quoted material from the CDC website. Walker did not like those CDC numbers. Discussion ensued regarding reported case numbers for each of the tick-borne diseases. Ben Beard suggested to just capture the big picture rather than talking about numbers in one year or another and stated ”diseases are on the rise and no one disputes that,” so why not just state ”cases over the past 15 years have increased significantly.” The co-leads will review that for inclusion.

The disagreements continued…In regard to Walker’s and Shapiro’s comments about NIH Lyme clinical treatment trials Cooper stated ” these are long standing professional disagreements.” Shapiro said “it could be presented in a much more balanced way”. Smith responded that they had already revised and made the changes as recommended. Shapiro stated “I’ll just write something…. a minority report I guess.” Smith said, “as long as you vote against this you certainly can do that. We indicated that there was a difference of opinion…and we did that. We felt that we addressed the huge discussion that was held last meeting…we looked back and read the summaries of the meeting…and we felt that we addressed those.”
Shapiro said “I vote no.” To which Pat responded, “you can’t vote no, there is no motion on the floor.” When asked by Dennis Dixon if there were any minor wording suggestions to take the need for minority report off the table, Shapiro stated “No, I don’t…I think it is too great a gap.”

When contrasting the differing treatment guidelines (IDSA vs ILADS), Shapiro commented, “again the authors ignore the fact that ILADS recommendations are gross outliers,” and that the authors have presented an “inaccurate, biased table” and he wants it deleted. After much discussion about the table’s contents and title, co-leads agree to revisit. Shapiro stated that he did not believe that information is being presented in a balanced way and that he will move forward with a minority report. Pat reminded Shapiro that to write the minority report, he will have to vote against the report.

On the topic of “shared decision making,” Walker proposed removal of the entire section. He stated that he “can’t see how this is relevant to this chapter.” He stated in the comments that “The authors of this chapter have departed from its intention…and that they have presented too much content on the ideas espoused by ILADS…” Walker further commented “This is an inappropriate balance. It represents a biased overemphasis on Lyme disease in the context of this chapter.” Pat Smith again championed the voice of the patients explaining why this content is not only appropriate but supports the intent of the WG.

Meeting Conclusion:

- Jim Berger announced that HHS will be seeking nominations in the next couple of weeks for TBDWG members for work on next report to Congress due in 2022. 4 of 7 public members terms expire Dec.2020 , other 3 in June 2021. Nominees will be asked to submit CV or Resume through a link in the Federal Register which will be open for 30 days.
Ben Beard announced the release of A National Public Health Framework for the Prevention and Control of Vector-Borne Diseases in Humans
https://www.cdc.gov/ncezid/dvbd/framework.html

The next meeting of the Working Group will take place virtually on October 27, 2020. Following meeting dates were also announced for November 17 and December 2, 2020.

*Slide presentations from the September 15th and 22nd meetings may be obtained by sending your request to tickbornedisease@hhs.gov.

MyLymeData 2019 Chart Book

TOUCHED BY LYME BLOG: Walker & Shapiro fail to change report’s Chapter 7

TOUCHED BY LYME BLOG: Will Working Group acknowledge patient voices?
First announced at the HHS Tick-Borne Disease Working Group’s (TBDWG) September 22 meeting, the Centers for Disease Control (CDC), in a Capitol Hill Announcement, presented plans to join with five federal departments and the Environmental Protection Agency in developing the National Public Health Framework for the Prevention and Control of Vector-Borne Diseases in Humans (Framework). The CDC acknowledges that over the past 15 years, the number of vector-borne disease cases has dramatically increased due to expanding vector ranges and the proliferation of emerging pathogens. The Framework will address Americans’ continually increasing risk for contracting vector-borne diseases, which are a growing public health threat that the U.S. has not sufficiently responded to.
The vision of the Framework is to achieve “a nation where vector-borne diseases are no longer a threat to human health and well-being” with a mission “to protect people from illness, suffering, and death due to vector-borne diseases” (CDC.gov). The CDC’s website outlines the following goals of the federal alliance:

- Better understand when, where, and how people are exposed to and get sick or die from vector-borne diseases
- Develop, evaluate, and improve tools and guidance for the diagnosis and detection of vector-borne diseases
- Develop, evaluate, and improve tools and guidance for the prevention and control of vector-borne diseases
- Develop and assess drugs and treatment strategies for vector-borne diseases
- Disseminate and support the implementation of effective public health and vector control products, tools, and programs to prevent, detect, diagnose, and respond to vector-borne disease threats – (CDC.gov)

**Strategy & Stakeholders**

The strategy, authorized by the Kay Hagan TICK Act of 2019, establishes priorities and lays a framework for critical vector-borne disease prevention and control activities. However, in their statement, the CDC acknowledges that the federal government cannot tackle the complex challenges presented by vector-borne diseases alone, and therefore outlines a multidisciplinary set of stakeholders including state, tribal, local, and territorial health departments; vector control agencies; healthcare providers; academic and industry partners; policy and decision-makers, including Congress and elected community leaders; public health partners, such as nonprofit organizations and associations of medical, entomological, and vector control professionals; and the public (including patients).

**Participating Federal Agencies & Departments**
Other federal agencies and departments participating in the Framework include Food and Drug Administration (FDA), National Institutes of Health (NIH), Department of Defense (DOD), Department of Agriculture (USDA), and Department of The Interior (DOI).

The CDC’s brochure for the National Public Health Framework for the Prevention and Control of Vector-Borne Diseases in Humans states that, “To protect the nation and save lives, success depends on continued collaboration, support, leadership, and excellence in innovation and program implementation.”

Learn More About the Framework
To learn more read the CDC’s brochure, A National Public Health Framework for the Prevention and Control of Vector-Borne Diseases in Humans from the CDC website.

Click here to review the National Framework fact sheet from the CDC website.

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Lyme Patients: Speak Up Now on Persistent/Chronic Lyme! Sept 4 Deadline

**Background:** The upcoming meeting of the HHS Working Group on Sept. 15 may be your last chance to influence language on persistent/chronic Lyme. At the last meeting, several members of the Working Group (WG) worked hard to have language related to
patients with persistent Lyme symptoms removed from the WG report which will go to Congress at end of year. Read more about the last TBDWG meeting.

At the upcoming September meeting, the WG will vote on proposed changes in language that can affect patient access to care. Please submit verbal or written comments now, deadline to request verbal comment or to submit written comment **11:59 p.m., ET, Friday, September 4, 2020.**

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**Meeting Details:** The fifteenth meeting of the Tick-Borne Disease Working Group (TBDWG) will be held on two non-consecutive days, September 15 and 22. This is an online meeting and everyone is welcome to attend. The TBDWG will review the draft 2020 report to the HHS Secretary and Congress, as well as review and approve graphics and images for the report.

Register to Attend the Online Meeting.

View the Federal Register Meeting Notice.

View the Meeting Agenda.

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**How to Submit Your Request for Verbal Public Comment at September 15 meeting (heard online at meeting):** Verbal remarks will be provided by the public over the phone during the live webcast and will become part of the archived recording and meeting summary that is posted afterward on the HHS website.

- **Deadline:** All sign-up requests must be received by **11:59 p.m., ET, Friday, September 4**
- **Submit an email request** to tickbornedisease@hhs.gov
- **Use the email subject line:** Verbal Public Comment – September 15
**Next steps:** If more requests to provide verbal public comment are received than can be accommodated during the meeting, speakers will be randomly selected. You will receive notification on the status of your request on **Wednesday, September 9**.

- **If you are selected to provide verbal public comment at the meeting,** you will be asked to confirm that you are still available to speak during the assigned time. Upon confirmation, you will receive a call-in number and time to provide your comment. Each person will be limited to 3 minutes in order to accommodate as many speakers as possible. If you are no longer able to provide verbal public comment, HHS will randomly select another speaker.
- **If you are not selected,** you are welcome to submit your name for consideration in a future meeting of the Working Group once the meeting information is posted.
- **Please note:** All public comment requests that were made for the postponed August meeting will be reviewed for possible speaking opportunity at the September 15 meeting. Those who did not request to speak at the August meeting may also apply to speak for the September 15 meeting.

**Please note:** All public comment requests that were made for the postponed August meeting will be reviewed for possible speaking opportunity at the September 15 meeting. Those who did not request to speak at the August meeting may also apply to speak for the September 15 meeting.

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**How to Submit Your Written Public Comment:** Written public comments are shared with Working Group members and are also posted on the HHS webpage. Written public comments will be made accessible to the public in advance of the meeting.
Submit an email to tickbornedisease@hhs.gov

Use the email subject line: Written Public Comment – September 15

Provide your preferred identification: Explain how you prefer to be identified with your comment. Without this information, your comment will not be posted. You may choose one or more of the following options:
- Use your name
- Be listed as anonymous
- Include your city and/or state
- Provide comments on behalf of an organization (please include the organization’s full name)

Deadline: All written comments must be received by 11:59 p.m., ET, Friday, September 4

Writing your public comment:

- Format: Comments must be in the body of your email or in an attached Word document.
- Page Limit: Comments must not exceed four (4) pages in Calibri or Times New Roman, 11 point font (text that exceeds four pages will be deleted).
- Graphics: Do not include graphics, images, text boxes, or tables. If included, they will not be retained.
- Links: Hyperlinks will only be added for “.gov” sites (local, state, or federal). For all other reference sites, please insert the full URL (e.g., http://learn.genetics.utah.edu/content/epigenetics).
- Attachments: Do not include any attachments. It is not possible to include attachments as supporting documentation to written comments.

Next steps: Your written comment will be posted to the HHS website before the meeting. If you have any questions or concerns about submitting your comment, contact tickbornediseases@hhs.gov.
In a complex government process, the Tick Act—a bill that provides funding for Vector-Borne Diseases including Lyme—was not fully funded according to the Committee report on HHS. The Committee report has 16M for Lyme and 38M for vector-borne diseases.

(NOTE: as LDA has mentioned in prior information on the Tick Act, it is for Vector-Borne Diseases of which TBD are only a part).

To address the issue, Congressman Chris Smith (NJ-4) developed an amendment to raise that funding for TBD, which was co-sponsored by Congressman Collin Peterson (MN). During amendment development, the President’s budget request for 2021 was examined, which asked for $14 million increase over 2020 for vector-borne diseases. Suggested funding levels in the Tick Act for vector-borne diseases were also examined. The LDA provided input into that amendment process and concurred with
an additional $11.4M to be asked for on top of the $2M increase in appropriations asked for in the report. Congressmen Smith and Peterson submitted the amendment for $11.4M, but Congressman Delgado (NY) also submitted an amendment, asking for $4M. The Congressmen agreed on $4M in an amendment Smith et al # 289.

Amendment # 289. Smith, Christopher (NJ), Peterson (MN), Stefanik (NY), Delgado (NY), Rose, Max (NY) does the following: Redirects $4 million from General Departmental Management at the Department of Health and Human Services to Emerging Zoonotic and Infectious Diseases at the Centers for Disease Control, for Lyme Disease and other Vector-Borne Diseases.

House Report 116-461, the Rules Committee Report on HR 7167, with amendments made in order, including the Chris Smith amendment. A description of the Smith amendment (289) is on page 33 of the pdf, and the actual language is on page 365 of the pdf.

Listen to the video below of Congressman Smith pitching the amendment to the committee.

GAO Investigation of Ticks/Vector-Borne Agents’ Biowarfare Experiments Passes
Update July 29, 2020: The Bill and passed amendments such as this one (below) has now moved to the conference committee where the House and Senate will work to decide what language goes into the final product. The LDA provided input into the amendment language and has been working to get Senators to champion the inclusion of this GAO Investigation Amendment into the final bill.

Said LDA president Pat Smith: “We thank Congressmen Smith & Peterson for championing this investigation. Lyme and tick-borne diseases (TBD) patients and the public are entitled to know the truth about what past government research may reveal not only about the documented tick releases along the Atlantic bird flyway but also about research on the mysterious ‘Swiss agent’ which Dr. Willy Burgdorfer identified as a new Rickettsia strain in his work for the US Government– at Rocky Mountain Labs and in Switzerland. Perhaps it may uncover clues to help stop this epidemic of tick-borne diseases.”

Rep. Smith (NJ-04) NDAA FY 2021 Lyme Disease Amendment Floor Speech

There is information in various publications that such activities did occur, especially in the book “Bitten” by Kris Newby—a science writer at Stanford University—a book, which explores the evidence through actual government documents and interviews with some researchers who were involved that document such experiments.

Said LDA president Pat Smith: “Lyme and tick-borne diseases (TBD) patients and the public are entitled to know the truth about what past government research may reveal not only about the documented tick releases along the Atlantic bird flyway
but also about research on the mysterious ‘Swiss agent’ which Dr. Willy Burgdorfer identified as a new *Rickettsia* strain in his work for the US Government— at Rocky Mountain Labs and in Switzerland. The book indicates there is speculation that this pathogen, if crossed with *Borrelia*, might well complicate treatment and thus be a candidate for biowarfare.” She added, “There is the possibility that any uncovered information could lead to facts which could shed light on the current epidemic of Lyme and other TBD and help develop solutions. We thank Congressmen Smith and Peterson for their continued push to make the truth known and the US House of Representatives for their vote to approve the amendment.”

Some things author Newby revealed for the first time were: that ticks were developed and deployed as stealth biological weapons during the Cold War, and that Willy Burgdorfer, the scientist the Lyme bacteria, *Borrelia burgdorferi*, was named after, was at the center of this program. According to Newby, specific revelations she makes in book include:

- A 1962 pilot study where infected ticks were dropped on Cuba sugar workers.
- Releases of hundreds of thousands of radioactive, aggressive Lone Star ticks on the Atlantic coastal bird flyway.
- Omissions of other microbes transmitted with Lyme-carrying ticks during the original outbreak (“Swiss Agent’).
- Documentation of military studies where live disease-causing bacteria, some which can be spread by ticks, were sprayed from planes, boats and vehicles on the unsuspecting American public.

In 2019, a similar amendment was introduced and passed the House unanimously but there was no senate support for it.

The Lyme Disease Association (LDA) has been encouraging Lyme advocates across the country to contact both of their US
Senators to champion and support this amendment. It is being heard in the Senate this week. LDA thanks those leaders who have made calls and sent emails to garner support.

More Information

New Jersey Globe: House passes Chris Smith measure to probe if government turned ticks into bioweapons

Chris Smith website: Chris Smith’s Lyme Disease Amendment Passes House, Tells DOD IG to Investigate the ‘Bioweaponization’ of Ticks


MoreMonmouthMusings.net: House passes Smith’s Amendment which could lead to a Lyme disease cure

Here is a very similar Smith amendment that passed the House unanimously in 2019 but did not make it through the Senate.

https://lymediseaseassociation.org/government/urgent-help-needed-for-biowarfare-investigation/

Kris Newby’s Bitten: LDA book review

All about Kris Newby, the book and access some of the documents used in book.
Pat Smith Describes Pre-Meeting Effort to Minimize Lyme.

Below in For the Record are the written comments LDA President Pat Smith, a public member of HHS TBD Working Group read (slightly compressed) into the record at the Working Group (WG) meeting on July 8 about the potential WG Chapter report for which she was responsible, the only one addressing patient issues. 89 written comments/deletions to the report had been suggested before the meeting by Working Group members. Working Group Co-Chair Dr. David Walker and Member Eugene Shapiro were responsible for moving to delete entire sections of Lyme material from the report, many of which called for the removal of much of the Lyme material and the de-emphasis of Patient Access to Care in the Chapter.

Co-Chair Says “almost religious belief that it’s a persistent infection”

At the meeting itself, Working Group Co-Chair, Dr. David Walker, and Member Eugene Shapiro made and seconded many motions to remove material from the proposed draft report including the two sets of guidelines, shared decision making, access to care, Lyme treatment trials, and cost of Lyme disease. There was also a discussion in which Shapiro and Walker wanted to remove Lyme mouse model studies and other animal studies that showed persistence that were included in the draft report, saying animal models were really not a good use for this infection.

Dr. Walker said there is “emphasis on belief...almost religious belief that it’s a persistent infection” and at various times said they probably didn’t have Lyme to start with. After many hours of this discussion, no other WG members would second the motions for removal.

For the record: The importance of today’s meeting and our Chapter review can’t be overstated. My Access to Care, Education & Training subcommittee including healthcare providers and patients, with expertise in the problems associated with patients’ access to care including physician education, submitted a 75-page subcommittee report and additional 45 citation pages documenting these problems to get
help for a body of patients neglected especially those who develop the most serious stage of Lyme and to prevent acute patients from reaching that stage. Patients looked to this WG created through legislation initiated by, written by, and pushed through Congress by Lyme patients/advocates. In 2019 through now, 78% of comments to the online WG mailbox were about TBD/Ticks, 70% of those TBD comments were on Lyme disease and 81% of those were on chronic/persistent/PTL, not acute.

Before the January 2020 Working Group meeting, WG members were instructed to read each subcommittee report. Subcommittee co-chairs presented reports at that meeting. In my subcommittee case, since I had not had an active co-chair for a while, a subcommittee member stand-in, not permitted to vote or ask questions, was allowed to present with me a PowerPoint, including Subcommittee rationale and recommendations later discussed, modified, and voted upon.

Then, writing groups of 2 WG members each were solicited for each Chapter to be written for the WG report to Congress. The WG was definitively told that all information for the WG report had to be taken from the Subcommittee reports. I asked if newly published information, for example, could be used, was told, yes, but then the WG would have to approve that new material. Recently activated WG alternate member Captain Scott Cooper and I volunteered to write the Chapter we’re presenting today.

As directed, we pulled language from the subcommittee reports, submitted our Chapter for review and was told “well organized, appropriate to audience level, and it flowed logically,” but we needed to “rebalance” the chapter as there was too much information on Lyme disease and access to care than other tick-borne diseases and education. Suggested rebalancing included removing a factual table from CDC which listed TBDs for 3 years, in descending order of reported case numbers, as the table could “inadvertently diminish the importance of
other tick-borne diseases because their numbers are much lower.” It was OK that we led with burden of disease (cost, quality of life, & productivity), compelling reasons for Congress to act. However, we should remove those items from our Chapter report background and put them into the background for the entire WG report, despite the fact they were developed specifically for our patient issues. Bottom line: minimize Lyme, reduce access to care.

We incorporated additional other TBD material from subcommittee reports into the Chapter and shortened the Lyme portion. We didn’t remove the table, since it factually portrayed reported case numbers, nor did we remove our background material germane for our specific patient issues. After another review submission, we were told the Chapter was “starting to become balanced” but now it was too long. We needed to shorten it. We again shortened to include removing the redundant list of recommendations upfront, already elsewhere in the Chapter.

All WG Chapter Writers had a deadline to post draft Chapters to a WG private Share Point site. WG members had a May 22 deadline to submit comments there on all chapters. All Chapter language was now up for grabs, we were told, even the language we took from the already discussed Subcommittee reports, not just new language. I objected, since that seemed to contradict process discussion at the prior meeting. Significantly, I objected to the lack of process transparency, which was directing these online SharePoint discussions to be behind the scenes—not WG members in public holding transparent discussion with all WG members, embodying the intent of a FACA Working Group. Time went by with no response to my objection, so I reluctantly decided to proceed with filing for resolution through a FACA complaint, but I was subsequently informed my concerns were heard, and all discussion would now be in public, as we are doing today so I did not proceed with the complaint.
While working in the private SharePoint site, I stumbled across an unknown person who had direct access to all Chapters and material in the site. Research showed me this individual was from NIH, not either the NIH Working Group member or alternate—a another NIH employee, an attorney. Upon questioning the individual’s identity and purpose, I was informed NIH requested that that individual be allowed access to our SharePoint documents and was given access. It appears that government employee WG members have rights public members do not have, are not aware of, and do not have to be informed of. Since public members are considered special government employees, I requested to federal officials that I be permitted to have a patient advocate attorney in SharePoint to review for patient perspective. I was informed my request was denied by WG legal counsel.

These items coupled with others such as a WG member who did not attend being allowed to vote by proxy through the co-chair, without knowledge of the WG, and the unexplained delay in releasing these draft Chapters to the public prior to this meeting for their review and comments before the WG vote are concerning, and refusal to provide the public with government inventories as agreed to at the April meeting. I questioned those practices, which in my opinion, exhibit a disregard for the public, in particular, the patient community. History coupled with these practices reinforce the sentiments of many in the public that they are again being deceived by their own government.

As we move forward on our Chapter section now, note that our printed report has 12 pages with internal citations to address the decades-long problems of hundreds of thousands of Lyme patients plus other tick-borne diseases patients. Additionally, there are 7+ printed pages of comments from SharePoint made by WG members on our Chapter, a number of which call for removal of much of our documented material on Lyme disease—a disease under-reported by a factor of 10
according to CDC studies and CDC testimony by Lyle Peterson to a Senate Committee, (1) meaning about 350,000 cases annually. According to NIH, Lyme is a disease that makes up 82% of tick-borne diseases, (2) and there were 74 Lyme deaths in 2017. (3) Thus, our Chapter focuses on the tick-borne disease whose patients comprise the largest burden of disease, Lyme disease. That is balance. Captain Cooper, I now turn further Chapter discussion to you.

(1) CDC Vector-Borne Diseases Director, CDC Lyle Peterson to the Senate Aging Committee September 5, 2019

(2) NIH says Lyme 82% of tick-borne disease cases

(3) NIH says 74 deaths in 2017. NOTE: I had accessed this info prior and printed out the information. Link no longer goes to the page. NIH asked at the meeting where I got that death data as they could not find it anywhere. I have sent it to them.

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
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)
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.

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Contentious Working Group Meeting Vote on CDC Posting Lyme Guidelines

The thirteenth meeting of the Tick-Borne Disease Working Group (Working Group) was held online on April 27, 2020, from 9:00 a.m. to 12:30 p.m., ET. This meeting was open to the public, with request to comment accepted by April 19, 2020.
HHS Tick-Borne Disease Working Group

The Working Group reviewed the work of the Public Comment Subcommittee followed by the Federal Inventory Subcommittee. The Working Group had sent inventories with a series of questions to the federal agencies, and the Inventory Subcommittee of David Walker (Chair), Sam Donta MD, and LDA President Pat Smith developed recommendations based on gaps in agency programs/research. The WG voted on the various recommendations for each agency to be brought forward in the Working Group Report to be submitted to Congress.

The Working Group members engaged in heated discussion regarding one recommendation “that IF the CDC posts any Lyme treatment guidelines, that they include guidelines on persistent Lyme disease.” Pat Smith, Lyme Disease Association President, argued persuasively on behalf of the chronic Lyme patient community, in favor of this recommendation. After the vote to pass the recommendation, some members wanted to change votes. So a member moved to revote causing a long discussion on the advisability/legality of such a vote. The Working Group federal official researched the question and indicated it was a dangerous precedent. Despite that, a revote was taken to permit a revote. It failed. So the original vote accepting the recommendation stands. Ms. Smith asked when the actual inventories would be released to the public, and after a discussion, the federal official indicated they could be.
Two Votes Taken

“Recommend that IF the CDC posts any Lyme treatment guidelines, that they include guidelines on persistent Lyme disease.” Pat Smith moved, Sam Donta, MD seconded the motion. Vote Results  6 YES, 3 NO, 5 ABSTAIN, 1 ABSENT

“Motion to have a revote on the last vote” Scott Commins, MD moved, Eugene Shiparo seconded the motion. Vote Results  5 YES, 6 NO, 0 ABSTAIN, 1 ABSENT

Roll Call Vote of Members

- Captain Scott J. Cooper, PA-C (government member) Centers for Medicare and Medicaid Services (CMS), HHS
  VOTE ON GUIDELINES RECOMMENDATION: YES  VOTE ON REVOTE: NO
- Angel M. Davey, PhD (government member) Tick-Borne Disease Research Program, Congressionally Directed Medical Research Programs, U.S. Department of Defense, DoD
  VOTE ON GUIDELINES RECOMMENDATION: YES  VOTE ON REVOTE: NO
- Dennis M. Dixon, PhD (government member) National Institute of Allergy and Infectious Diseases (NIAID/NIH), HHS
  VOTE ON GUIDELINES RECOMMENDATION: YES  *post vote, wanted to change to Abstain  VOTE ON REVOTE: NO
- Sam T. Donta, MD –Professor of Medicine (ret.) (public member)
  VOTE ON GUIDELINES RECOMMENDATION: YES  VOTE ON REVOTE: NO
- Patricia V. Smith- (public member) Lyme Disease Association, Inc.
  VOTE ON GUIDELINES RECOMMENDATION: YES  VOTE ON REVOTE:
Charles Benjamin (Ben) Beard, PhD (government member)  
Division of Vector-Borne Diseases, Centers for Disease  
Control and Prevention (CDC)  
VOTE ON GUIDELINES RECOMMENDATION: NO  VOTE ON REVOTE:  
YES  
Eugene David Sharpiro, MD  (public member) Yale  
University School of Medicine  
VOTE GUIDELINES ON RECOMMENDATION: NO  VOTE ON REVOTE:  
YES  
David Hughes Walker, MD, (public member) TBDWG co-chair,  
UTMB Center for Biodefense & Emerging Infectious Diseases  
VOTE ON GUIDELINES RECOMMENDATION: NO  VOTE ON REVOTE:  
NO  
Scott Palmer Commins, MD, PhD (public member) –  
University of North Carolina  
VOTE ON GUIDELINES RECOMMENDATION: ABSTAIN  VOTE ON  
REVOTE: YES  
CDR Todd Myers, PhD (government member) Food and Drug  
Administration, HHS  
VOTE ON GUIDELINES RECOMMENDATION: ABSTAIN  VOTE ON  
REVOTE: YES  
Adablbeto (Beto) Perez de Leon, DVM, PhD (government  
member) Department of Agriculture (USDA), HHS  
VOTE ON GUIDELINES RECOMMENDATION: ABSTAIN  VOTE ON  
REVOTE: YES  
Kevin R. Macaluso, PhD, MS  (government member)  
University of South Alabama  
VOTE ON GUIDELINES RECOMMENDATION: ABSTAIN  VOTE ON  
REVOTE: NO  
Leigh Ann Soltysiak, MS (co-chair) (public member)  
Silverleaf Consulting, LLC Adjunct Professor, Stevens  
Institute of Technology  
VOTE ON GUIDELINES RECOMMENDATION: ABSTAIN  VOTE ON  
REVOTE: YES  
Leith States  (government member) Deputy Chief Medical
The TBDWG, received verbal comments from the public on a range of topics including:

- Dorothy Leland, Vice-President of Lymedisease.org presented for Phyllis Mervine, President of Lymedisease.org comments on the need for Lyme disease treatment guidelines similar to COVID-19 guidelines as posted by NIH. She stated COVID-19 won’t stop tick season, and for Lyme disease treatments, ultimately the choice of what to do for an individual patient should be decided by the patient and their treating physician, just as it is recommended in the COVID-19 NIH treatment guidelines.

- Lucy Barnes, Lyme advocate, presented comments on the Infectious Diseases Society of America’s (IDSA’s) outdated Lyme treatment guidelines, which she stated has discredited anything, and anyone, that disrupts their status quo, often resulting in name calling and demeaning the character of both patients and their treating physicians.

- Beth Carrison, from TBC united, commented on the unique health challenges faced by Alpha-gal patients in light of the current COVID-19 treatments. She pleaded for an urgent Health Alert to be posted in order to help protect these at risk patients.

- Stephen Rich, professor of Microbiology at University of Mass, TickReport Lab commented on the value of tick testing and prevention messaging that accompanies their tick testing reports. He urged the CDC to review their stance against tick-testing.
The meeting concluded after updates on the status of the writing groups for each of the assigned chapters being developed for the 2020 report to Congress on federal tick-borne activities and research. The next public virtual meeting is scheduled for July 8, 2020.

LDA encourages patients, advocates, caregivers and family of Lyme disease patients to submit verbal or written comments about Lyme disease to the TBDWG for the July 8th meeting and to attend the meeting online.

Read Lymedisease.org VP, Dorothy Leland’s, Bizarre happenings at the TBD Working Group Blog here.

Read Lymedisease.org, President, Phyllis Mervine’s, NIH’s COVID-19 guidelines offer useful advice for Lyme disease, too Blog here.

Visit the HHS TBDWG webpage for more information, including how to submit verbal and written public comments.

Click here to view information about prior TBDWG meetings.

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**President at COVID-19 Event: Lyme is Serious!**

President Trump hosted Michigan State Rep. Karen Whitsett – who credits his promotion of a malaria drug, hydroxychloroquine, with her recovery from coronavirus – and other COVID-19 survivors at the White House. During their informal discussions, Rep. Whitsett, who nearly lost her life to COVID-19, brought up her chronic Lyme disease as an underlying condition. Throughout the 41-minute meeting,
President Trump highlighted how serious and devastating Lyme disease is, stating that it “can kill you”.

LDA President Pat Smith said, “It is a good thing for Lyme patients that the President is speaking about how serious Lyme disease really is—the message coming in an unscripted discussion on another serious disease sweeping the world, COVID-19, which preys heavily on those with chronic conditions. Lyme is often not included in that category but is looked upon by many in mainstream medicine and in government as easily cured with a few weeks of antibiotics, a myth still existing after 45 years of Lyme disease.”

Pat Smith continued, “Patients succeeded in getting an HHS Working Group formed to address the issues of Lyme and other tick-borne diseases but there is still strong resistance to Lyme getting the attention it requires—still being marginalized despite about 350,000 cases occurring annually in the US alone. The President’s open interest and willingness to discuss it publically as being serious should put all levels of government on notice that it is critical chronic Lyme disease be addressed.”

Remarks by President Trump in a Meeting with Recovered COVID-19 Patients

Excerpts of Lyme Disease Discussion During Meeting (below video)

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EXCERPTS OF LYME DISEASE DISCUSSION DURING MEETING

**STATE REPRESENTATIVE WHITSETT**: The shortenings of — the shortening of breath is what really got me afraid because I do have Lyme disease. And thank you for always mentioning about Lyme disease.
THE PRESIDENT: Yeah. Yeah. No, Lyme disease is a big deal.

STATE REPRESENTATIVE WHITSETT: Thank you for always bringing that to the forefront.

THE PRESIDENT: Do you think you still have Lyme disease?

STATE REPRESENTATIVE WHITSETT: I do. I have chronic Lyme disease because I was never treated in time.

THE PRESIDENT: Can that be — can you get rid of it?

STATE REPRESENTATIVE WHITSETT: I’m hoping that we’ll talk about that.

THE PRESIDENT: Lyme disease is a thing that people don’t talk about. It is brutal —

STATE REPRESENTATIVE WHITSETT: It is brutal.

THE PRESIDENT: And if you have a certain type of blood, you have no chance.

STATE REPRESENTATIVE WHITSETT: It’s brutal. It’s brutal. And then, on top of having COVID-19 with it, it is a nightmare.

THE PRESIDENT: Incredible.

STATE REPRESENTATIVE WHITSETT: But the breathing is what scared me the most. And it came — I went from 0 to 100. It was from getting tested that day on March 31st to trying to do a few things around the house, to just all of a sudden my breathing became labored.

(Later In Discussion)

THE PRESIDENT: Yeah. No, if — by the way, we have tremendous endorsements. But if it were somebody else other than President Trump that put it forward — if some other person put
it forward, they’d say, “Oh, let’s go with it.” You know.

What do you have to lose? They’ve been taking it for 40 years for malaria, which — by the way, it’s an unbelievable malaria pill. Unbelievable lupus pill. Unbelievable. In fact, the problem we had is people with lupus —

STATE REPRESENTATIVE WHITSETT: And with Lyme disease.

THE PRESIDENT: Huh?

STATE REPRESENTATIVE WHITSETT: And with Lyme disease. It was (inaudible) with Lyme disease.

THE PRESIDENT: And with — I heard Lyme disease, too.

(Later In Discussion)

THE PRESIDENT: I’m a little surprised they can’t do something with your Lyme disease. The Lyme disease is really terrible.

STATE REPRESENTATIVE WHITSETT: That’s because that’s federal. I need you.

THE PRESIDENT: Yeah. Well, but —

STATE REPRESENTATIVE WHITSETT: I need you on that.

THE PRESIDENT: — I mean, I could even have you see the doctor over here, because White — White House doctor. Ask the White House doctor to come.

PARTICIPANT: (Inaudible.)

THE PRESIDENT: Seriously. Because Lyme disease can be very, very bad.

STATE REPRESENTATIVE WHITSETT: Yeah. I don’t have a doctor any longer.
THE PRESIDENT: But it also can be — it also can — is it legal for me to allow her to use the White House doctor? You know what? If it’s not, I will suffer the repercussions. (Laughter.) I don’t care.

STATE REPRESENTATIVE WHITSETT: Well, there are —

THE PRESIDENT: The Democrats might not like that.

STATE REPRESENTATIVE WHITSETT: Well, there are a lot of people in Michigan and I do have eight Lyme bills that I am putting forward for Lyme disease —

THE PRESIDENT: Very good. Do it.

STATE REPRESENTATIVE WHITSETT: — because you cannot get treated in Michigan, as a doctor sees fit, for Lyme disease.

THE PRESIDENT: People don’t know about Lyme disease. It’s a very bad —

STATE REPRESENTATIVE WHITSETT: It’s horrible.

THE PRESIDENT: — very bad thing. And it —

STATE REPRESENTATIVE WHITSETT: So it is something I’m working on.

THE PRESIDENT: But it is something, over a period of time, you can treat generally. It also can kill you. Lyme disease — if you —

STATE REPRESENTATIVE WHITSETT: Yes.

THE PRESIDENT: If you have a certain type blood, you get Lyme disease —

STATE REPRESENTATIVE WHITSETT: Yes.

THE PRESIDENT: — it’s over.

STATE REPRESENTATIVE WHITSETT: I’m glad you know that.
THE PRESIDENT: It’s literally over.

STATE REPRESENTATIVE WHITSETT: I’m glad you know that.

THE PRESIDENT: I think type O — type O blood is not too good. If you have type O blood, stay out of the woods. Right?

STATE REPRESENTATIVE WHITSETT: It’s not even the woods. I got this at home at five years old.

THE PRESIDENT: You got it at home?

STATE REPRESENTATIVE WHITSETT: In Detroit.

THE PRESIDENT: But usually it’s from a deer tick, right?

STATE REPRESENTATIVE WHITSETT: It is a deer tick.

THE PRESIDENT: So where did the tick come from?

STATE REPRESENTATIVE WHITSETT: Well, the tick does not discriminate. It will get on anything.

THE PRESIDENT: So it comes somehow, right?

STATE REPRESENTATIVE WHITSETT: Yes. A squirrel, a bug, a bird — anything. It doesn’t discriminate.

THE PRESIDENT: Well, it’s like when I hit a ball into the rough in golf. (Laughter.) You know what I say? “Enjoy yourself. I’m not going in there.” (Laughter.) That Lyme disease is pretty tough, right?

STATE REPRESENTATIVE WHITSETT: It is.

THE PRESIDENT: It’s a bad one. I’d like you to see our doctor before you leave, okay?

STATE REPRESENTATIVE WHITSETT: Thank you.
(Last Statements on Lyme)

THE PRESIDENT: But what do I know? Am I allowed to take Karen over to see the White House doctors, see if we can help her out a little bit with Lyme disease? Because Lyme disease is a problem and there are some answers. What do you think? Are you guys going to report me for being a horrible human being? For doing something illegal? Did I do something illegal?

Q We can’t advise you on that, sir.

THE PRESIDENT: And then impeach me. Then you’ll impeach me because I tried to help her out with her Lyme disease. Do you think maybe? Because I’d like to do that. What do you think? Should I do it?

Q I can’t advise you on that, sir. But I — I certainly hope that she —

THE PRESIDENT: See, they never like to take chances, but I do. So, we’ll take a chance on it. Okay?

See Also: Rep. Smith Questions COVID-19’s Impact on Lyme Patients

Rep. Smith Questions
COVID-19’s Impact on Lyme Patients

On April 9th, Rep. Chris Smith sent a letter to Health and Human Services (HHS) Secretary Alex Azar and the National Institute for Allergies and Infectious Disease (NIAID) Director, Dr. Anthony Fauci, thanking them for their tireless efforts to address the Coronavirus outbreak as well as expressing his concerns about Lyme disease sufferers and their potential to be especially vulnerable to COVID-19.

Smith wrote, “As you know, my home state of New Jersey has been ravaged by COVID-19—as of April 9 there have been 51,027 confirmed positive cases and 1,700 have tragically lost their lives. Thousands more have lost their lives across the entire Tri-State area which also includes New York and Connecticut. I find this outbreak especially concerning when I consider the countless individuals who live in this region who also suffer from Lyme Disease, which also considers the Tri-State Area as a ‘hotspot.’”

The letter highlighted a 2018 HHS Tick-Borne Disease Working Group (TBDWG) report to Congress indicating that there are approximately 300,000 new cases of tick-borne disease annually in the US. Smith warned this number is likely higher and a press release from his office states that an estimated 40,000 of these cases originate in New Jersey.

“I remain deeply concerned about what impact COVID-19 and the Coronavirus outbreak will have on the countless Americans suffering from Lyme Disease and other related coinfections,”
Smith continued. “Does the National Institutes of Health believe Lyme Disease, and other tickborne diseases, are considered underlying conditions which put individuals at higher risk for COVID-19?”

Since 1993 Smith has consistently worked to address the needs of the Lyme disease community including authoring comprehensive amendments and legislation such as the *Lyme Disease Initiative Act of 1998* and more recently, *The Tick Act*, which creates a “new whole-of-government” national strategy to combat Lyme and other tick-borne diseases.

Read Congressman Smith’s letter to NIH and HHS.

Read a Press Release about Congressman Smith’s letter.