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…”
- “SeroLogic diagnostic testing and CDC guidelines are
inaccurate and hurting many people”
- 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

![Tick-Borne Disease Working Group](https://www.cdc.gov/ticd/images/slide.jpg)

- “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?
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
Jul 21, 2020

Congressman Christopher H. Smith (NJ-04)


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.

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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.
Lyme Vaccine Candidate: Valneva Announces Phase 2 Study Results

Valneva announced that the vaccine candidate against Lyme disease, VLA15-201, showed positive initial results meeting its endpoints in the Phase 2 study. They stated in the July 22, 2020 press release that “compared to Phase 1, the higher doses used in this trial elicited higher antibody responses across all serotypes.” Of particular note was the immunological response found in older adults (50-65 years), one of the main target groups for a Lyme vaccine. The vaccine candidate is described as “generally safe across all dose and age groups tested”, finding no Serious Adverse Events (SAEs) associated with VLA15. This is an important finding given the history of vaccines and serious concerns that have been generated regarding patient safety and vaccines in the Lyme community.

VLA15 is the only active Lyme disease vaccine candidate in clinical development today, covering six serotypes of Lyme disease prevalent in North America and Europe. It was granted Fast Track designation by the U.S. Food and Drug Administration (FDA) in July 2017. In a few months, Valneva expects to report top-line results for the second Phase 2 study, VLA15-202. Valneva and Pfizer are collaborating for development and commercialization of VLA15.

Read full July 22, 2020 press release here

Read Valneva vaccine history and Lyme Disease Association’s concerns here:
Johns Hopkins’ Aucott Makes Case for Chronic Lyme Disease

John Aucott, Director, Johns Hopkins Lyme Disease Research Center and Associate Professor of Medicine, Johns Hopkins University, published a piece in The Conversation providing his insight on the highly controversial topic of chronic Lyme disease.

In the article, Aucott outlines the existence of a population of patients – an estimated 10-20% – with persistent, lingering symptoms months to years after treatment. He details some of his experience treating these patients and provides an explanation of the various challenges that impair the diagnostic and treatment process. Aucott states, “My chronic Lyme patients were sicker and had less hope than the AIDS
patients I worked with, but the underlying mechanism of illness remained elusive.”

Aucott emphasizes that while the mechanism of chronic Lyme disease remains unknown, and molecular markers are needed to provide further insights, it is “no longer accurate to simply argue that chronic Lyme disease doesn’t exist.”

Read Aucott’s full article in The Conversation.

Visit LDA’s web page with more information about the chronic Lyme controversy.

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**Torrey vs. IDSA/Insurers Lawsuit Update: Cigna Third Insurance Defendant to Settle**

The Lyme Disease Association is providing the most recent update regarding Torrey vs. IDSA/Insurers, the federal lawsuit filed by 24 Lyme patients against six members of the Infectious Disease Society of America (IDSA) and eight insurance companies in the U.S. District Court for the Eastern District of Texas, Texarkana Division.

According to investigative journalist Mary Beth Pfeiffer, Cigna has now become the third insurance company defendant in the case to settle following Kaiser Permanente in November
2019 and Blue Cross Blue Shield of Texas (BCBST) in January 2020. Pfeiffer reports that, as was the case with the first two, the Cigna settlement is being handled in secret with sealed documents. The public may never know what the plaintiffs received, or what was accomplished during the hearings. The remaining defendants include the IDSA, five other insurance companies, and six Medical Doctors.

At this stage, this is all the information that has been made available. Details regarding the terms or amount of the settlements are unknown. The lawsuit was initially filed in 2017 on behalf of the group of Lyme disease patients who claim they have been denied care, as well as harmed, under existing insurance and medical protocols. The litigation proceedings will continue in the U.S. District Court in Texarkana, Texas.

LDA will provide updates when we have them. You can also continue to watch for updates on Mary Beth Pfeiffer’s website and Twitter feed.

Click here to view the Notice of proposed settlement of Cigna Health and Life Insurance Company.

Click here to view the Notice of settlement of BCBS of Texas.

Click here to view the Settlement reached with Kaiser Permanente.

Referenced articles and websites:

3. LymeDisease.org. TOUCHED BY LYME: Latest in anti-
Rodent-Targeted Bait Vaccine Shows Decrease in Lyme Disease Transmission

The Connecticut Agricultural Experiment Station (CAES) and US Biologic, Inc. released the publication of a field trial study showing the effectiveness of an orally-delivered anti-Lyme vaccine that targets the white-footed mouse, the major wildlife source of Lyme disease.

The study took place in the residential area of Redding, CT, over a three-year time period and showed substantial decreases in the number of infected mice. One year into the study, test sites that had been treated with the vaccine showed a 13X
greater decrease in blacklegged ticks (*Ixodes scapularis*, the primary vector associated with the spread of disease) infected with *Borrelia burgdorferi* (the bacterium that causes Lyme disease) compared to control sites (i.e., 26% drop versus 2% drop).

“Fewer infected ticks mean less infection in the field overall,” says Dr. Kirby C. Stafford, Chief Scientist and State Entomologist, “So the decrease would be greater year-over-year that the vaccine is applied.”

A second effect, which has been observed in previous laboratory-based studies showed that the vaccine causes the mice to generate antibodies and therefore previously infected ticks act as a ‘xenodiagnostic marker’ of vaccine impact, meaning once they ingest the antibodies, while feeding on vaccinated mice, the ticks then become ‘cleared’ of infection.

Dr. Scott C. Williams, Agricultural Scientist and co-author of the study verified that when non-infected mice feed on vaccine-coated pellets, they are then protected from the *Borrelia burgdorferi* infection. “Non-infected ticks, therefore, cannot pass the disease to other animals, including humans” he says.

The study’s findings were published in the peer-reviewed publication, *Experimental and Applied Acarology*. Click here to view the press release from The Connecticut Agricultural Experiment Station.

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Recently, two documents were filed electronically by the suit’s mediator. The first announces that Kaiser Permanente, one of the eight insurance company Defendants, has settled with the Plaintiffs. The second stated that the mediation session, which commenced in February of this year, has been suspended, and that “the undersigned mediator will continue to work with the parties in an effort to settle”.

More recently, according to Investigative journalist and author, Mary Beth Pfeiffer, “Proceedings have again been delayed, to 2/14/20. Parties will report by 1/31/20 on ‘agreements and/or differences concerning the case schedule, the amount of time necessary to finish discovery and trial timing.’”

At this stage, this is all the information that has been released to the public. Details regarding the terms or amount of the settlement are currently unknown. The lawsuit was initially filed in 2017 on behalf of the group of Lyme disease patients who claim they have been denied care, as well as harmed, under existing insurance and medical protocols. The
Research Review Finds IDSA Guidelines Contribute to Mental Health Epidemic
Researchers, including Robert C. Bransfield, MD, Lyme Disease Association Professional & Medical Advisory Board Member, recently reviewed the proposed new Lyme Disease Guidelines, a 100 page document on the prevention, diagnosis, and treatment of Lyme disease drafted by the Infectious Disease Society of America (IDSA) in collaboration with the American Academy of Neurology and American Academy of Rheumatology. The draft of the IDSA Guidelines was released for public comment in August of 2019 and received a considerable number of responses from the Lyme community, many critical of the proposed Guidelines.

The review was published in Healthcare Scientific Journal and scrutinizes specific sections of the guidelines that are most relevant to psychiatry including the disclaimer, laboratory testing, and adult and pediatric psychiatric sections. The researchers have outlined many issues with the IDSA Guideline draft, most notably, the failure to outline the causal association between Lyme disease and psychiatric illnesses throughout, despite the vast amount of well-founded supporting evidence.

The Disclaimer

According to the researchers, the proposed disclaimer, which was more extensive than the one on past IDSA guidelines, contained many issues, including failure to state that the guidelines cannot be used to establish a standard of care. The analysis found that the disclaimer offered no type of warranty of accuracy or reliability with the methods outlined and that
the institutions responsible for creating the guidelines held themselves harmless from any potential losses that may occur when practicing physicians use the guidelines to treat patients. The seriousness of the guidelines issue came to the attention of the US Health and Human Services Tick-Borne Disease Working Group (TBDWG), of which LDA President Pat Smith is a member, and discussion was included in the group’s 2018 Report to Congress.

Diagnostic Testing

According to the researchers, one of the most central flaws contained within the guidelines was the recommended use of the scientifically unfounded surveillance case definition as diagnostic criteria. The IDSA Guidelines make the incorrect assessment that patients who do not meet the surveillance case definition for Lyme disease do not meet clinical diagnostic criteria either, and therefore, do not have Lyme disease. Additionally, the review calls attention to issues with the IDSA’s arbitrary focus on 2-tiered testing as a reliable method of diagnosis.

Testing Adults with Psychiatric Illness for Lyme Disease

The IDSA Guidelines advise against testing for Lyme disease in adults with diagnosed psychiatric illness, yet a number of studies show a causal relationship between Lyme disease and certain kinds of psychiatric illnesses. Prior research has shown that a low prevalence of mental illness may exist prior to infection while the presence of psychiatric illnesses and comorbidities is more significant post-infection.

The researchers were able to identify 377 unique citations on the ILADS website, supporting an association between Lyme disease and psychiatric illness. However, the IDSA Guidelines include only a small number of articles limited to epidemiologic studies that selectively reported outcomes

Testing Children with Developmental, Behavioral, or
Psychiatric Disorders for Lyme Disease

The IDSA Guidelines also recommend against standard testing for Lyme disease in children with developmental, behavioral, or psychiatric disorders, referencing that there is no data to support a causal association between tick-borne infections and behavioral disorders or developmental delays in children. However, as the researchers who analyzed the IDSA Guidelines state, the IDSA included no references to support these claims and in fact, numerous articles demonstrating the causal relationship between Lyme disease and developmental, behavioral, and psychiatric disorders in childhood do exist.

References:


“Bitten” Book Review
The debate over the prevalence of Lyme disease and whether it exists in a chronic form has raged for decades. Kris Newby’s well researched book provides documented evidence that the suspicions of disease sufferers, their advocates, and treating physicians deserve investigation. The properties of the pathogen itself and its ally, the tick, appear to be part of our nation’s biowarfare studies.

Swiss American scientist Willy Burgdorfer is acclaimed for identifying the spirochetal bacteria which causes Lyme disease. Indeed, the pathogen bears his name, *Borrelia burgdorferi*. Yet as the author discloses through filmed interviews and archival reviews, there were other aspects to Willy’s research. Employed by the US government and headquartered at Rocky Mountain Laboratories, Burgdorfer was enmeshed in biological warfare projects. Ms. Newby discusses his work in Switzerland for the American government which led to the identification of a new strain of *Rickettsia*, a pathogen if crossed with *Borrelia* might well complicate treatment and thus be a candidate for biowarfare. Interviews by Ms. Newby with American researchers on the topic of the *Rickettsia*, dubbed the Swiss agent by Dr. Burgdorfer, did not shed any light on the mystery pathogen whose existence seems to be buried in the past.

Ms. Newby’s discovery of tick drops and the experimental release of ticks document ongoing biowarfare research and questions the consequences if studies go awry. The prevalence of new diseases and the expansion of tick territories are examined in the context of now revealed government studies.

Ultimately, whatever mix of causes is responsible for the Lyme and other tick-borne diseases epidemic in the US, the
solutions, as strongly stated by Kris Newby, lie with better science, advanced research and proper funding.

Click here for YouTube video of Under Our Skin, Director, Andy Abrams and Kris Newby discussing her new book.

Click here to purchase Bitten on amazon.com

Click here for other purchasing options of Bitten on HarperCollins.com

L. Johnson on Meaningful Patient Representation on the next TBDWG

Lorraine Johnson, JD, MBA, Chief Executive Officer of LymeDisease.org delves into the importance of meaningful patient representation on the Federal HHS Tick-Borne Disease Working Group (TBDWG) in her latest blog. This is especially important as we await the announcement of panelists to the new TBDWG charged with the next report to Congress due in 2020. A recent patient survey conducted by lymedisease.org found “To be a meaningful representative, patients chosen for a panel should: a) have or be a caregiver to a patient with chronic Lyme disease and b) should be an officer or director or someone vetted and approved by a recognized and trusted
patient advocacy group (PAG) or someone approved by a PAG.” Read the entire blog by Lorraine Johnson here:

https://www.lymedisease.org/who-represents-lyme-disease-patients/