

**Tick-Borne Disease Working Group
10:03 AM to 11:07 AM**

>> Kristen Honey: With this next stake holder perspective I would like to introduce Dr. Catherine Brown from the Council of State and Territorial Epidemiologists. She is on the phone, not here in person, so we will virtually welcome her.

Dr. Catherine M. Brown is the Deputy State Epidemiologist and State Public Health Veterinarian for the Massachusetts Department of Public Health. She has oversight of surveillance for and education about zoonotic and vector borne diseases in Massachusetts, and participates actively through the Council of State and Territorial Epidemiologists in national discussions about tick borne diseases.

CSTE is a member based organization representing applied public health epidemiologist at state, territorial, local, and tribal health departments. CSTE promotes the effective use of epidemiological data to guide public health practice, and improve health. CSTE supports effective public health surveillance, and good epidemiologic practice through training, capacity development, and peer consultation. Let's welcome Catherine.

[applause]

>> Catherine Brown: Good morning. Can everyone hear me okay?

>> Audience: Yes.

>> Catherine Brown: All right, thank you. I certainly wish that I could be there in person, but I would like to convey my deep appreciation for the invitation to present to the working group on behalf of the Council of State and Territorial Epidemiologists on this very important topic of tick borne disease challenges to public health.

And just to get started I want to let you know that I have spent the majority of my public health career in Massachusetts, which is one of the states most heavily impacted by Lyme disease. And I have spent countless hours speaking with residents who are actually afraid to go outside due to the risk of Lyme disease. I have spoken with health care providers who are frustrated by the limitations of Lyme laboratory diagnostics, and with patients who are continuously struggling with the effects of the disease.

But I also have to say that I actually live here in Massachusetts as well. Work is not my entire life. And Lyme disease has a personal impact on me, my family, and my friends. So, because of all of this I really care passionately about this issue as do my many of my colleagues. And I hope that what I share with you today can assist the working group as you move forward with your efforts.

Second slide, please. So, just as quick review the Council of State and Territorial Epidemiologists, affectionately known as CSTE, it's an organization of epidemiologists at state, territorial, local, and tribal health departments, and it serves as one of the institutions that helps

advocate for public health at all levels.

The organization is engaged in many activities, but there are two that are especially important for today's discussion. And the first is that CSTE actively promotes the effective use of epidemiologic data to help guide public health practice, and improve health. And, these are things that are especially critical in today's world of big data and near real time information sharing.

The second activity of particular importance for today is that CSTE supports effective public health surveillance, and epidemiologic practice by providing and facilitating training opportunities which include peer to peer consultation, and the aim of this is to develop capacity at all jurisdictional levels of public health. Next slide, please.

So, within public health practice as a whole, epidemiologists are linked to several essential public health services. And these are first to monitor community health status, and burden of disease in order to first identify problems. Second, to diagnose and investigate health problems and hazards that are occurring within those communities, to further describe those problems, and then to work with partners to develop effective interventions, which leads to the third essential service, which is informing, educating, and empowering people around those health problems, and the necessary interventions. And this all actually comes back full circle, because epidemiologists need to continue to monitor health status, so as to assess the effect of those interventions, and adjust them as necessary, in an iterative process. Next slide, please.

So, many of you may know this already, but for those of you who are not sort of immersed in the work of public health, I want to convey to you that in order to perform these essential services, public health departments have a broad authority to collect data for use in preventing and controlling disease in order to protect the public's health.

And so, state and local health jurisdictions are authorized to receive information about cases of reportable disease from both diagnostic laboratories, and health care providers, and to use that information to investigate cases, identify case contacts who might require care, trace outbreaks, and identify emerging diseases, or unusual manifestations of disease.

And you know, this authority to collect data carries with it a really great responsibility to each individual patient. So, public health practitioners are required by law to collect only those data which are necessary for the public health function, and also not to release information that results in the identification of an affected individual. But we also have the extraordinary responsibility to use those data in proactive ways, to help improve the lives of individuals. Next slide.

So, public health surveillance, and that's really the performance of the identification and monitoring essential services that I mentioned previously has, as we all know, shown national increases in first and foremost Lyme disease. But then, also in other diseases that -- some of which impact my jurisdiction, so anaplasmosis, babesiosis, Powassan Virus, and the spotted fever rickettsiosis disease. And then, if that weren't enough, we have also been identifying new tick borne diseases that have to be added to the list. And some of these include Bourbon virus, heartworm virus, *Borrelia Mayonii*, and *Borrelia Miyamotoi*. Surveillance has been absolutely

critical to detecting and then monitoring trends over time and space of these diseases.

Now disease surveillance requires the use of standardized case definitions. And these definitions are absolutely critical and necessary to produce data that can be compared year to year, but also between jurisdictions. I think some confusion sometimes arises in that these definitions are specifically designed for surveillance purposes only, and not for diagnostic purposes. And I know that folks at the Center for Disease Control, the people that I work -- represent at the Council of State and Territorial Epidemiologists, and local, state, and tribal, and territorial public health departments, all strive to ensure that that both health care providers and patients understand that there is a clear distinction between case definition standards and clinical diagnosis.

So, these case definitions require that we collect both laboratory and clinical information, not all of which may be obtainable, or even available for every patient. And in states with a high incidence of any tick borne disease, the burden of this surveillance falls upon public health, health care providers, and reporting laboratories, and data are therefore often incomplete. However, the data that are available are critical for defining risk factors for disease, and for development of specific preventive messages, and these data also serve as a platform for research. Next slide, please.

So, the surveillance data that have been collected on all tick borne diseases have contributed extensively to knowledge about the need for and development of two primary intervention tools, that are available to public health, to help mitigate the impact that tick borne diseases have on communities. And this brings us, really, to the third essential service of epidemiologists that I mentioned previously, which is informing, educating, and empowering people around the health problems and the interventions. And in this case these efforts are targeted at education of health care professionals about the changing distribution of disease, and emerging tick borne diseases, and education of the public about the true critical need for tick bite prevention. Next slide, please.

So, the surveillance data that have been collected have also helped inform public health of some critical needs. And this is absolutely not an exhaustive list, and nor is it intended to be. I think it will also echo some of the comments that you've heard previously, but the gaps that I'm going to address are really specific to surveillance activities, and to primary prevention, preventing people from being exposed to the disease in the first place.

So, we need better diagnostics, especially for diseases like Lyme disease, where diagnosis is based on antibody detection, rather than pathogen detection. We need improved access to laboratory testing for emerging diseases such as Powassan, rather than trying to rely on just a few centralized laboratories.

We need continued support for development of public health infrastructure with less focus on disease specific resources, and more broad-based support, so that individual jurisdictions can direct resources at the places where -- that they identify they have the biggest gaps.

The use of electronic health records and real-time disease reporting processes through electronic

laboratory reporting and mining of the electronic health record data is critical to the sustainability of surveillance, and needs to be prioritized for development.

We desperately need basic research into methods of effective vector control, and in this case I mean tick control, so that we finally could have some tool that could be applied on a community level, rather than relying on personal, the personal prevention messages that we have right now. And we need assistance with outreach to achieve widespread behavioral changes around the use of those personal prevention methods. Because even if we get effective vector control and a vaccine we are probably still going to need to rely on personal prevention.

So, that concludes my remarks today, and I really want to reiterate my deep appreciation for the invitation to speak with you, both on behalf of CSTE, and as a jurisdiction that is in the heart of the struggle with Lyme and other tick borne diseases. Thank you very much.

[applause]

>> Kristen Honey: Thank you very much, Catherine. And next up is we have the final stakeholder perspective, Dr. Sarah Vetter with the Association of Public Health Laboratories. Sarah, please -- oh, she's on the phone. We have another virtual presentation.

So, Dr. Sarah Vetter is the Chief of Infectious Diseases at the Minnesota Department of Public Health Laboratory. The Association of Public Health Laboratories, or APHL represents state and local governmental health laboratories in the United States that monitor, detect, and respond to health threats. APHL works to strengthen laboratory systems serving the public health in the United States, and also globally. Welcome, Sarah.

>> Sarah Vetter: Thank you. Thank for this opportunity to speak with you all today. APHL strongly believes that building and maintaining a comprehensive surveillance system for the detection of endemic and emerging tick borne diseases, and investing in the development of new diagnostic approaches is critically important to maintaining the public's health.

The current U.S. surveillance system includes a limited number of states that receive federal funding to conduct tick borne disease surveillance, despite the emergence of new tick borne diseases, and the fact that the areas in which ticks are found continue to expand.

The availability of diagnostic tools and guidance on the use of diagnostics for emerging tick borne diseases such as Bourbon virus, heartland virus, Rickettsia Philippi, and Borrelia Miyamotoi is extremely limited, and while the available diagnostic tools and guidance on more common pathogens such as Lyme disease are due to be updated to reflect technological advances.

The first recommendation to the working group is to build the capacity to detect and respond to all tick borne disease of public health significance. This means to define and institute a comprehensive and adaptable tick borne disease surveillance system that incorporates epidemiology, laboratory, and entomology resources for the accurate and timely detection, characterization, and response to tick borne disease in the U.S; have the ability to characterize

the regional differences in tick vector prevalence, and the associated pathogens in order to enhance understanding of the role that different ticks species may play in the perpetuation of tick borne diseases in their respective geographic regions.

And finally, to learn the prevalence of the pathogens in vectors, and how this prevalence varies geographically. The data on prevalence of pathogens in vectors can be used to guide enhanced surveillance for disease in humans, and focus tick control efforts if resources are limited.

The second recommendation is to encourage the development and use of new or improved diagnostic tools, or the advancement of diagnostics currently in the pipeline to improve the accuracy, and/or the rapidity of tick borne disease identification; integrate new laboratory diagnostic capabilities into tick borne disease surveillance programs as emerging novel pathogens are discovered.

Once a cluster of rare disease caused by an uncommon pathogen is identified, perform enhanced active surveillance. We can use technologies that detect multiple pathogens simultaneously. This is important, since early intervention and treatment is critical, yet early signs and symptoms of many of these diseases are similar.

Multiplex assays, if sensitivity and specificity can be maintained, offer the potential to rapidly rule in or out tick borne pathogens, and reduce turnaround time to diagnosis.

We suggest fostering and open dialog between diagnostic manufacturers, diagnostic laboratories, and FDA to able, to encourage the mission and clearance of assays that fill gaps in the marketplace. And we'd like to suggest to increase the appropriate use of recombinant proteins that improve the specificity for serologic assays. As an example, panels of recombinant proteins have been shown to be more specific than a whole *Borrelia Burgdorferi* lysis in serologic tests for diagnosis of Lyme disease. Recombinant Lyme blot assays have greater specificity than western blots, with whole *Borrelia* extracts.

The third recommendation is to encourage widespread access to high quality laboratory tools. This includes the enforcement of existing mechanisms to ensure diagnostic tools currently in use meet minimum quality standards; developing mechanisms to promote use of standardized reagents to ensure results, analysis, and interpretations are consistent across all laboratories performing testing; ensuring broad geographic access to quality diagnostic testing for all tick borne diseases, through the establishment of laboratory networks, with the expertise to perform specialized or enhanced testing, and characterization of these diseases, and to establish national training programs for tick borne disease testing.

The fourth recommendation is to develop updated or new testing guidelines for tick borne diseases, and implement mechanisms to allow for rapid updates when warranted. Consider establishing a mechanism that allows for rapid updates to guidelines as novel tick borne pathogens are discovered, technology advances are released, or additional laboratory testing information is available.

The fifth and final recommendation is to improve guidance for and education of clinicians on the

most appropriate use and interpretation of available diagnostic tools. Different test methods are best used in different disease stages. For example, PCR may be the most sensitive method to diagnose disease in early acute samples, whereas serological testing may be preferred for later samples. Different specimen types may be required for these alternative methods. Inappropriate test ordering can lead to missed opportunities to diagnose cases.

This concludes the recommendations from APHL, and again I'd like to thank you for your time.

[applause]

>> John Aucott: So, that ends the stake holder presentations. We're going to transition now to another round of public comment. And just reviewing how that went yesterday was wonderful to have our expert facilitator. Today we'll have semi-expert facilitators with Kristin and myself.

So, we'll just remind everyone that this is a time of chance to hear public comment, and we all approach this with openness and respect, and mostly gratitude that the people here today are willing to share in front of the public their experiences and their comments, and we just look forward to hearing more of that. The time allotted for each presentation is three minutes, and we'll begin with public comment now.

>> Kristen Honey: Excellent; thank you, John. And as John said, three minutes each. He will be time keeper. He'll be roaming around, and we have a few late signups for public comment, and if people keep to three minutes we believe we'll be able to fit everyone in.

So, first up, let's hear from Gil Lake [phonetic sp], and please self-introduce yourself, because all I have is first names, so thank you, Gil.

>> Gil Lake: Hi, my name is Gil Lake. Thank you for your attention. I am not truthcures.org, but I gain great knowledge from that organization concerning Lyme disease.

Respectfully, I have crawled 3,389 kilometers on Wounded Knee, and no spleen to lie to you today. A long, long time ago my great Uncle Sam had a saying, and it goes as thus: we the people of the United States, in order to form a more perfect union, establish justice, ensure domestic tranquility, provide for the common defense, promote the general welfare, and secure the blessings of liberty to ourselves and our posterity, do ordain and establish this Constitution for the United States of America.

Please consider the exit, ye who wrote in on the proscription of the Dearborn Conference, amongst you, if any. Misfeasance, malfeasance, and non-feasance are casus belli in any other scope, a cause for war to promote this for decades, and not actually do anything about it.

The Osp A disorder, for example -- and expressed in a pandemic form, however you do that, but it's all over; it's not just in western Michigan where I got the tick, I had to move completely out of my territory into the desert just to survive. I didn't have a doctor. I still don't have a doctor. It's not available to a very large portion of our society. I don't know if you guys are aware of that.

You all have doctors, you all have lawyers, and collectively you have a lawyer. I don't know why there isn't one on the panel. I don't know why there isn't a psychiatrist on the panel to differentiate some of this cognitive dissonance that is promoted through the CDC, et cetera. All these corporations have got their own agenda. And it's not the same as mine. I just want to survive to tomorrow. And I want to -- and I've had neighbor, neighbor, neighbor, die from this affliction. And it doesn't seem to rattle any cages back home.

They aren't -- when I was a truck driver, as a CDL driver of hazardous materials the very first thing we had to do if there was a problem is -- not even if there was a problem, is to notify the public. You placard the vehicle.

Placard; give everyone attention to this very, very important matter. Thank you.

[applause]

>> Kristen Honey: Thank you, Gil. And we are giving it our attention, and every perspective, like, counts, so thank you for sharing yours. Jenna Luche Thayer, you're up next. Jenna?

>> Jenna Luche Thayer: Let's see here. Hi, my name is Jenna Luche Thayer. And I have worked globally for 32 years on the rights of the marginalized, and held senior advisory positions for the U.S. Government in the United Nations, and I'm the founder and director of the Ad-Hoc Committee for the Health Equity in the ICD-11 Borreliosis codes, and the global network on Institutional Discrimination. And my expertise includes human rights and transparency and accountability of governance.

So, according to one of many odd articles that has been sponsored by 32 million dollars in NIH grants, translational research grants, I'm also "nefarious," and "dangerous," and I'm being sponsored by unknown and powerful sources. So, I just want you to know that my husband has invited everyone to our house for a barbecue, so you can know who he is.

Anyway, to day, I'd like to talk about some observations and solutions to enhance representation, transparency and accountability in the process that we're undergoing, and I'm using my expert hat on this. I have personally participated in numerous federal advisory boards, and I know that federal law recognizes two valid and distinct options for public members who are participating. One can be either a representative, or a special government employee.

A representative provides the points of view of non-governmental entities and/or a recognized group such as Lyme patients, people who treat Lyme, et cetera; doctors who especially treat those who persist in complicated forms of the disease, advocates who are perhaps promoting valid diagnostic tests such as the nested PCR/DNA sequencing technologies that uses direct detection and is currently available, and can actually identify the illness before it disseminates.

In contrast, a special government employee, which is what the current public members have been asked to do, promote government interests first, and are under the supervisory and operational control of the agency, in this case HHS, even on the days when they are not serving on the

working group.

And as employees, their wide ranging restrictions include legal, financial, representational, and research limits. For example, they are not allowed, according to the law, as an SGE, to testify against Department of Health Officers, or government line policy, or on behalf of the human rights defenders of this group. And when I talk about that human rights defenders I talk about the researchers, the scientists, and the practitioners of health, who are getting much needed care to this patient group.

They are not allowed to generate earnings from research presentations, publications, and media events that counter the Lyme -- the CDC's Lyme propaganda. They are not allowed to state that the CDC Lyme policy does not support human rights violations, or ignores the many potentially fatal medical conditions caused by Lyme. And I want you to know that these are all on record since June 2017. They were accepted by Dr. Dainius Puras, who is a special Rapporteur for health and human rights.

So, given these considerations and options, I recommend that all members be converted to representative status. Thank you.

[applause]

> Kristen Honey: Thank you, Jenna. Next up we have Rachel Nevitt.

> Rachel Nevitt: That's Rachel Nevitt for the record. Me too; I have been violated by multiple individuals multiple times, and I am not alone. My perpetrators are repeat offenders, hailed as pillars of the medical world, they are the righteous keepers of the Infections Disease Lyme Guidelines. They are the definitive authorities. They are the priests, the uncles, the Harvey Weinsteins, and they abuse their power.

We know in part that they are perpetrators because they do what every good perpetrator does, they deflect their guilt by blaming the victims, the patients, who are condescended to -- "Lyme doesn't cause those symptoms," ridiculed -- "Oh, did you find that on Google?" and written off -- "It's not Lyme, it's conversion syndrome."

And just to make sure that the perpetrators preserve their air of superiority, they constantly discredit and de-legitimize the Lyme specialist, who threatens their impervious shields with scientific evidence to the contrary.

I have attended numerous talks by infections disease doctors, and Dr. Christina Nelson of the CDC, all of whom spent more than 50 percent of their talk making it very clear to their audiences -- medical students, and primary care providers, that Lyme practitioners are quacks, who have gone rogue off the guidelines, and will endanger patients' lives with their treacherous protocols.

Then, you have these treacherous protocols, are the very same prescribed long term by dermatologists for teenagers with acne, by infectious disease doctors for patients with TB, by PCP's for seniors suffering from frequent urinary tract infections. But for some reason if a Lyme

doc prescribes it for a bacterial infection it's considered life threatening.

If I had cancer, doctors would think nothing of prescribing toxic cocktails that might save me, because presumably it might make be better than my current cancer ridden self. Well, that's where a lot of Lyme patients are at. When I found myself so sick that death looked like a better state than the life I was subjected to, me the antibiotic free organic farmer, subjected myself to antibiotics for one of the first times in my life.

I subjected myself for three years straight, lots of them, in crazy doses I can't even imagine. And you know what? Under my Lyme doctor's care, I did not get C. Diff, my PICC line did not get infected, and I am so much better than I used to be. Truth: my Lyme doctor did not kill me. My Lyme doctor did not harm me. My Lyme doctor used careful treatments that have been proven to make some folks better without making them sicker. My Lyme doc saved me while other local doctors left me to get sicker.

There's something seriously wrong with a medical system that allows infectious disease doctors, rheumatologists, neurologists to diagnose psychiatric disorders but won't let a Lyme doctor diagnose Lyme. There's something wrong with a medical system that punishes good doctors who think critically and question the perpetrators, and listen to the victims. It's time to stop the madness. It's time to reveal the serious perpetrators. It's time to openly admit that this medicine is seriously flawed. It's time to stop blaming, and start listening to the hundreds of thousands of victims. It's time to call off the medical boards and let the good doctors, the critical thinkers, take the lead and heal the sick, and start healing this very bad chapter in our medical history.

The day of reckoning will come. The culture of cover up is crumbling everywhere, even here in Washington. Perpetrators are being held accountable, victims are being believed. So, ask yourself: when the day of reckoning arrives which side do you want to say you were on?

[applause]

> Kristen Honey: Thank you, Rachel. Thank you, Rachel, for sharing your story, your courage -- everyone who's speaking up. We have Enid Haller next, and then John and I are going to switch roles.

> Enid Haller: Thanks, Chris. It's Enid Haller, and I have a masters in social work, and a Ph.D. in clinical psych. I am on the Board of the Dean Lyme Center, and have been a Lyme advocate for nine years.

For the last 11 years I've lived on Martha's Vineyard. And I have been trying to educate everyone on the Island about chronic Lyme disease. I started the Martha's Vineyard Lyme Support Group nine years ago, and the Lyme Center of Martha's Vineyard five years ago.

During that time I've only received help from and support from the alternative and holistic practitioners, and including physical therapists, naturopaths, chiropractors, et cetera. The Martha's Vineyard Boards of Health, the island's community services, the local doctors, and health care providers, and in the walk in clinics, and Martha's Vineyard Hospital, have been of no

help to our chronic Lyme sufferers for over 30 years.

Most people I know who have chronic Lyme on the Island, including myself and my family, have never tested positive for chronic Lyme using the two tier testing model, the ELISA and the western blot.

I was not -- it was not until I suggested the island patients start to use the IGeneX lab that we all finally started getting the correct diagnosis. Confusion in the medical community has been compounded by the actions of insurance companies who have both denied patients important care, as well as proactively threatened and revoked the licenses of doctors who engage chronic Lyme patients seriously.

This has created fear among the mainstream doctors, and has created an increased the rate at which normal, easily treatable acute cases of Lyme have gone chronic. My support group has 859 names on the mailing list, and we are not alone. There are thousands of Lyme support groups across this country and the world that provide support at this scale.

The number of people in Martha's Vineyard who carry chronic Lyme disease, and the co-infections boggles the mind. Many of the patients on the Vineyard believe that they were infected from the LYMERix vaccine that was heavily given years ago, only for a year. But many do believe that they have contracted it from the vaccine.

The Lyme stricken patients travel from one specialist to another until their patience and budget strains to the breaking point, or they just suffer in denial and silence. The treatment of choice then becomes self-medication through alcohol and pain killers, which are typically opiates. It personal -- at personal cast of our inability to systematically cope with this growing disease is staggering.

I've been directing chronic Lyme sufferers to Lyme literate doctors for many years now --

>> Kristen Honey: Three minutes.

>> Enid Haller: Okay, that can afford -- but most cannot afford to travel and see these doctors who have to charge out of pocket due to the lack of insurance coverage for chronic Lyme.

Finally, we are at the tipping point, and the Island medical community is slowly begging to acknowledge the depth of this problem. Martha's Vineyard is known as ground zero for chronic Lyme, because towns are all in the top ten list of the Massachusetts Department of Public Health: one: Tisbury, two: Aquinnah, three: Edgartown, and ten: West Tisbury. The Lyme fiasco is a financial and economic disaster. Insurance companies would save money if they would allow Lyme literate doctors to share their knowledge, and be accepted into the system. Our mainstream doctors need to be helped and educated about how to diagnose and treat chronic Lyme.

This is a terrible disease, and the situation can be turned around. With the proper incentives and honest medicine, millions of people can get their lives back, and an equal number can be

prevented from suffering so badly. And if I -- if myself and my family had not gone to Dr. Richard Horowitz, I would not be here today. Thank you.

[applause]

>> John Aucott: Thank you, Enid, very much. Our next comments will come from Susan Green [phonetic sp].

[applause]

>> Susan Green: Good afternoon, and thank you for your service. My name is Susan Green. I'm an attorney, and I've been practicing law for more years than I admit at this stage of my life. I also am a Lyme patient.

Approximately 10 years ago I was in the middle of a trial. I had a seizure. I lost my ability to speak and retrieve language, curled up in a ball, and all of my limbs were twitching, and I would remain that way. My memory was completely wiped out. I would remain that way for quite some time.

I went to doctor after doctor, same story; nobody knew what was wrong with me. Finally, I begged a doctor to give me antibiotics. He was infectious disease doctor. He said to me, "You don't have Lyme disease," he says, "but you're so hysterical, I'm going to give you another test. And I'm going to give you the antibiotics just to calm you down." Very reputed doctor at John Hopkins; so he gave me the test, and he gave me the antibiotics.

You can imagine his surprise when several days later, Wednesday at 6:30 in the morning, he called me and told me I was off the charts. I had had four prior tests, they were all negative. He -- I went to his office, and I had the most unusual experience.

He leaned across his desk, and he pushed a barrel of antibiotics at me, and he said to me, "I can't treat you. You're a very, very, sick woman," and he said, "But I would be drummed out of my society if I were to treat you with long term antibiotics. I'm very sorry. You're going to have to find another doctor." And I went from state to state, looking for a doctor who could take care of my needs.

I would be 20 months of IV antibiotics, and 72 hyperbaric oxygen dives before I would resume my ability to speak. I do believe I would be dead today, but for the doctors who risk their licenses to treat me.

We have a terrible problem. As an attorney I told all these doctors, "If you get me back my ability to speak I will help you." Because these doctors come under attack from medical boards on a regular basis. They come under attack simply because they prescribe long term antibiotics.

It's insane to me that a child with acne can get a year of antibiotics to treat their skin, but a person with a progressive and potentially fatal disease cannot get treatment for more than 28 days because we are the only population that seems to get the superbugs. It doesn't make any

sense, okay?

So, I defend doctors' licenses before the medical boards. Many patients who saw that their doctors were going to be in jeopardy of losing their licenses gave gone around the country and passed laws to protect doctors who proscribe long term antibiotics.

Everybody, the whole community would celebrate when these laws were passed. But I'm here to tell you that it hasn't stopped the medical boards. Because what they have done now is they go around, and they charge these doctors with -- they hold them to a higher standard of care. They engage in a discriminatory practice of singling out these doctors based solely upon the type of medicine that they provide.

And now they will go into their charts, they'll hold them to a higher standard of care, and they'll charge them with coding violations, record violations, record keeping violations, and they are still in danger of losing their license. They spend exorbitant amounts of money defending themselves just be able to serve the community. I ask that you unfetter the hands of these doctors who are on the front line of battling, trying to find a treatment, and help these very sick and marginalized people. Thank you.

[applause]

>> John Aucott: Thank you, Susan. Next comments will come from Linda Osborn [phonetic sp].

>>Linda Osborn: I just need to get me laptop, because my notes are on there.

>> Kristen Honey: Move the microphone done so people can hear you.

>> Linda Osborn: Thank you very much for the opportunity to speak today, and I'm delighted to see this collaboration of individuals working on this tremendously important issue.

My name is Linda Osborn, and I'm a resident of Hunterdon County, New Jersey. I live with my husband of 23 years, and my 19-year-old daughter, who is currently attending the University of Delaware. If it wasn't for finals she would be in attendance with me.

My story is similar to the many you've already heard. I was misdiagnosed for probably at least two decades, maybe longer, due to false negative results produced by recommended two tier testing. The exact timeframe of my infection is unknown. But I do recall when I was about 10 my parents removing an embedded tick from my head, and that was in 1974.

I was 10. I don't recall a lot of details from that time, but I do distinctly remember that year I received my first C on my report card. And I was pulled aside by my teacher for some moral support, and TLC. I was off. And she could see it.

Let's fast forward. In my early 20's I spent many hours rock climbing, hiking, mucking about the gunks in New Paltz, New York, and in Vermont, and other parts of New England. I was always

outside. And it was then I started noticing some cardiac symptoms.

By my late 20's I became depressed, and shortly thereafter was diagnosed as bipolar. I believed that that diagnosis set the trajectory for the next decade of horrific experiences that I had with M.D.'s and specialists. What happened is my mental health was designated as my illness, when in reality, my undiagnosed illness was causing my mental and physical decline.

Where my story diverges from others is that I did have a very difficult childhood. There was in fact a degree of mental dysfunction that resulted from the challenges of my earliest years. I was a product of my environment, and therefore I accepted my diagnosis, and continued in a downward spiral with a growing list of physical symptoms and behavioral changes.

But here's the key point: despite the challenges that presented my life in my first 20 years, I was never suicidal. I was bullied, I was teased, but at that time there was no internet. However, guess what? There were bathroom walls, and that was the 70's and '80's version of Snapchat.

The key point here is that I became suicidal once I got into the advanced and late stages of Lyme disease after not having been diagnosed for over 20 years. And what made that insult to injury worse was that I infected my only unborn child through pregnancy and/or breastfeeding.

So, as I lay in my bed, uncomfortable in my skin, misery, with trying to get through the treatment of this insidious disease, I wanted to kill myself, but I couldn't, because I had to stay in this world long enough to be able to help my daughter through this insidious disease, and at the same time contemplate whether she was also having suicidal thoughts.

Gentlemen in the room, I would like you to sit and think about your wives, and your children, and think about what it must be like to wonder every day when you come home from work, whether you're going to find your wife in bed, dead from an overdose, or your child swinging from a tree in the backyard.

This is the reality of what this disease does to people when it is not diagnosed. And I will add: I did see in LLMD, and I did go for alternative testing, and I was tested positive for Lyme, for Rabezioal-1 [phonetic sp], or Brucella, for Mycolpasma Pneumo, for HVV-6, for and MTRF gene mutation, for candida overgrowth, high levels of lead, high levels of mercury, adrenal failure, kidney failure, liver failure.

I did extensive antibiotics that brought me back to life. I was pulled out of the grave. But I will tell you, I'm not cured, either, and nor is my daughter, who finally tested positive after several rounds of antibiotics. Thank you.

[applause]

>> John Aucott: Thank you, Linda. Jennifer Heath [phonetic sp].

>> Jennifer Heath: Hello. Thank you all for having me be able to speak today on behalf of all us that are sick and dying with Lyme disease that are not being diagnosed properly, or treated.

Thank you for sharing your story, because people are dying. The number one cause used to be heart attack or stroke. Now it is suicide because people can't get the treatment they need.

My personal journey began dealing with Lyme disease, not knowing that I had Lyme disease, in 2013 when I became deathly ill after having a routine dental cleaning, and I found a root canal tooth, the crown of it had to be removed and replaced. When they did that the infection went into my body. I got very sick, went to doctors, ended up in the hospital; was said that I needed to have a hysterectomy, had that, almost died with an infected abscess hematoma.

After that was -- fortunately the doctor on call made a lifesaving decision that saved my life that had a surgery, that -- they thought it was just an abscess, but when they got in there it was an infected hematoma abscess.

So, I was asked if I wanted a chaplain. I said no, because I was prepared to die. I wanted to die at that point, I was so ill. And I'm thankful to say that I didn't because I got see my granddaughter recently, just born. That was something that I didn't think I would ever see possible.

So, I went through a year and a half of doctor, after doctor, specialist after specialist, trying to figure out the next set of, like, four cancer scares. The next doctor I was going to see was an oncologist. But unfortunately, I ended up in the ER, and when I -- I had just had the ELISA test that -- I was one of the fortunate people that, 15 percent of the population only are seronegative - - I mean seropositive.

So, I actually had an antibody response. And so, the CDC called me, asked me if I was out -- ever went outside of our county, and I'm like, of course. I just went up at my daughter's destination wedding.

So, I asked them who can I go to, because in the ER, in the emergency room when I told UFM that I had -- I needed extra tests for Lyme disease, the western blot, they said that they don't diagnose nor treat Lyme disease in the ER.

And the next person that I had to see was an infectious disease doctor, that had a three month waiting list, and I didn't have three months to go, because at that point I'd had already done two weeks of antibiotics, and I started throwing up for nine days straight, and I was left to die.

I had great doctors before that, but everyone that I went to and talked to, when I mentioned Lyme they go, "You know what, I'm sorry. We don't treat Lyme disease," you know, like, "We'll help you, we'll run tests or whatever, but we don't diagnose nor treat Lyme disease." So, I didn't know where to go.

So, praise God, I have been on my health journey for 30 years. I've worked with renowned nutritionists and holistic doctors, and so I went from doing the western medicine that almost killed me, for a year and a half I went back to holistic medicine, and I started treating it holistically with deep tissue cleansing, enzymes, and oxygen treatments, things that are voodoo to our medical world, and that need to be implemented. And I thank God for Dr. Horowitz that

does that, that brings that in, because we need more practitioners like that, and I [unintelligible] actually recognize that this is more severe. So, I just want to thank you.

But yeah, right now we have this fake Lyme -- it's funny that there's no proper testing for Lyme disease, but right now the CDC is test marketing a new vaccine for Lyme disease, but how can you test for a disease that you don't even know how to test for? How can you make vaccine against something that you don't know what to test for? So, you know, I think that we need to revisit that, and call your Congress people, and ask them to investigate the two tier testing, because that testing is flawed, as we all hear here. People are not being diagnosed. They're being left to die. So, thank you so much for letting me speak.

[applause]

>> John Aucott: Thank you. Jennifer Leblanc [phonetic sp]

>> Jennifer Leblanc: Good morning. My name is Jennifer Leblanc. I'm currently an infection control practitioner at the University of Maryland Medical Center. My bachelor's degree is in molecular and microbiology. I have a master's degree in clinical nutrition. I attended a three and a half years of medical school, and recently I was blessed enough to have graduated from the Johns Hopkins Bloomberg School of Public Health.

My story starts when I -- I was born and raised in South Florida. I became ill when I was about seven or eight years old. My family often went camping in the swamps of Florida. I soon had neck pains, went to doctors after doctor. My mom brought me for one of the necks, no one could figure it out. One pediatrician thought, "Well, maybe you should have exploratory spinal surgery," and my mom said, "I don't think so."

Nevertheless, I had symptoms that waxed and waned. When some symptoms would disappear, several months later, or even years later, more symptoms would come back. And then they'd be worse. And then my symptoms would go away, and they would come back, and they would bring friends.

Well, since I was a pre-med, you know, I was going to this conference where Dr. Oz was presenting, and that's how I found the doctor who diagnosed me. And I said, "Great, I have an answer, Lyme disease. And how do we treat that?" And he's, like, "Oh well." And so began my additional frustration of this journey.

Well, I soon discovered a wonderfully courageous physician who demonstrates not only courage and persistence, but wonderful faith as well. And it is because of him that I am standing here, not in pain. I am standing here speaking, I am seeing, and I am breathing. And I say that because I was having seizures at which time I stopped breathing. I was driving on the highway, at which time I stopped seeing. I went completely blind on two separate occasions. I had a hard time walking. I felt like my legs were jello and would give out any time.

I couldn't come up with a sentence, and here I am speaking in front of all of you. And so, it is because of physicians like those who represent ILADS that I am standing here, that these patients

are still alive and breathing. And when I was at Hopkins, we have to do a capstone project. And last year there was a publication in the New England Journal of Medicine, and I became very frustrated. And I said, "You know, why don't we just clean the slate? Let's start over again." So, for my project I want to go ahead and say, "All right, let's put everything on the table. Here's the IDSA side, here's the ILADS side. And this is what I want my research proposal to be for my capstone project."

The directors of the Infectious Diseases Capstone Project literally laughed at me. And I knew their response when I would ask this question. But I said, "Doctor so and so, can I ask why you laughed?" And she goes, "Well, let's just say I don't believe in chronic Lyme. It doesn't exist." And I said, "Ok, well, that's what I thought."

What we need is education. I have educated over a 140 medical students on the accurate information Lyme disease. There are hundreds of publications that represent what many of us are talking about here today.

>> Kristen Honey: Three minutes

>> Jennifer Leblanc: I would like us to further diagnostic testing by using metabolomics, nanoparticles that are already being investigated. We need to take advantage of the brilliant minds of the epidemiologists and public health sector, who can help us identify exactly where these pathogens are. And I promise you that that CDC map will be not just blue in this corner, and that corner, and the other corner; it will be pretty blue.

So, I -- with my three minutes up, I just encourage all of us to continue to work collaboratively, and include the public health sector, and educate those who are in medicine, and entering medicine. Thank you so much.

[applause]

>> John Aucott: Thank you, Jennifer. Christine Lorenson [phonetic sp].

[inaudible commentary]

>> Male Speaker: One more, I'm not going to do the additional [inaudible].

>> Christine Lorenson: Hi. My name is Christine Lorenson. I believe I was born with tick borne illness. I experienced excruciating pain as a child, that no one took seriously. I had one known bite as a child, but it wasn't until I got bit by something in Costa Rica that I was unable to function.

I have my struggles dealing with the roller coaster of treating and relapsing, dealing with insurance denials. After finally starting to improve on a treatment regimen and tough conversations with my husband, when paying out of pocket is the only option, I often feel like my treatment is at the mercy of what my insurance company will pay for, not what is most effective for my treatment.

But I'm still one of the lucky ones. I'm lucky because I'm alive, and I'm here today. So many do not make it. The ability to get coverage for treatment, the lack of acceptance and knowledge, the loss of function, the pain, the loneliness, the bullying by doctors who follow outdated guidelines, and ignore new research, who send us for psych consults, it can be too much for our bodies and our minds to handle.

I am here today to give voice for those who are no longer able to fight. The current situation is not working. We are at a point where doing nothing is no longer an option. I ask the working group members to put aside greed, ego, and politics. This is an epidemic and one that can be solved if everyone puts forth the effort to do the right thing in an open minded collaborative manner.

My friend's daughter, Keara Mitchell was one of the ones we lost this year. She was a young woman who contracted tick borne diseases as a child, in New York, as did her sister and brother. Keara was 19 years old. She should have been in the prime of her life, but instead dealt with severe effects from Lyme and co-infections.

In honor of her, her family started Keara's Traveling Stones. People leave a stone in some place they think Keara would love to have been well enough to visit. If I may, I'd like to give each of the members of the working group a stone in honor of Keara, who I believe would have wished to be here to witness this historic collaborative effort, to bring forth change that she knew was so desperately needed.

I ask you to keep it as a reminder of the thousands that we've lost, especially those who can -- who choose death, because the pain of living and loss of hope was too great to bear. They will not be forgotten. Thank you.

>> John Aucott: Thank you.

[applause]

>> John Aucott: Our last comments will come from Bob Sabatino.

>> Bob Sabatino: Thank you. I'm going to try to keep myself short, and on my own time. I would like to thank members of the armed services that are here, and members of nonprofits and research organizations and doctors.

I'm here both as a patient and an advocate. I am the Founder and Director of Lyme Society in New York. I've had what I would call pleasure of meeting many of you already, people in this room and people watching.

A few years ago, I had the pleasure of meeting Kristen Honey. I don't know if it was at an open data event, or a Lyme event, but every single one has always been positive.

I started out very sick, very ill, Lyme and co-infections. For everyone that knows me this is

probably the best shape I've ever been in, right now, and I'm still treating, every day's hard. I couldn't be here yesterday, so I thank you for the time today. Through our time this is one of the most unique opportunities I've seen happen. I've known over many years it's been very difficult for two sides to come together.

This is so important for everyone to see. I've had the luxury of working with many of you, and I say a luxury, because being the patient and being that sick, I go home every day. And at the end of the day I don't wear the hat of a husband, a father, an advocate. It's a patient. I start it that way, I end it that way, and it's something I live with.

But as an advocate, all I have seen in the past few years is positive actions coming from the Lyme community, because there's the opportunity to hear two sides of a story. There's an opportunity to work together.

As Kristen said yesterday, let's hit the reset button, let's start something new. There is an opportunity to have a change. If we redefine it, we redefine it. But for patients suffering, ill, going through the changes -- I have a device in my chest. I've lost my knees. I've lost my shoulders. I had Bell's palsy. I had all the symptoms that many here have suffered worse than me. But I am here today.

There is that fighting chance to do something. And I applaud you all for being in the working group, and I just hope that everyone around the country sees this as something that's going to change; two sides three -- whatever it is, is going to come together, listen, and help each other for the patient.

My treatment has not been the normal treatment. The normal treatments did not function properly for me, they didn't work. The unorthodox way that we have worked it together has made a difference. That doesn't mean it's going to fit patient A, B, and C. But it fit me.

I'm shorter than your time, and I want to keep it that way. I wasn't able to make it. I thank you all for the opportunity, and I applaud you for what you do, and if there's anything I could ever do to help anyone I would love the opportunity. And again, everyone: keep fighting the fight. We're all here together. There will be a change. Thank you.

>> John Aucott: Thank you very much.

[applause]

>> John Aucott: That's a wonderful note to end the public comments on. We're going to wrap things up here.

>> Kristen Honey: So, yeah, just on the comments there. I wanted to reflect on a couple themes that we heard. One is such powerful, powerful stories. Thank you for having the courage to publicly share, and constructively offer solutions.

A lot of the themes through those individual stories is the mental health, the suicide aspects, the

invisible pain. So, I was thinking we could reset before we go into the charter, the working group, by taking 60 seconds to just reflect on one, those people who can't physically be here with us, but who are holding the space for, and we are working for; and also our hope, what we reflected on yesterday, and what we want out of this.

If we could go back to what we want, and where we're going with this reset, and with this working group, in 60 seconds before we go to the charter, I'd appreciate that. Thank you, everyone, and John will close it out before we break, and then we'll get to the real work.

>> John Aucott: I just want to end by saying that the public comments are an important part of this, and that's why we've devoted appropriately, time for this. I want to ensure you that as the working group chair, that we're listening, and that it makes a difference to have had the courage to come today. We're listening, we're hearing what you're saying, and it's an important part of what we'll be doing, is incorporating your comments. So I really want to emphasize that, that this wasn't just an exercise. It was part of us hearing you, and we will be taking into the way we work as a group, so thank you very much.

We'll go to break, now.

>> Male Speaker: U.S. Department of Health and Human Services, produced at taxpayer expense.

[end of transcript]