

**Tick-Borne Disease Working Group
2:43 PM TO 3:34 PM**

>> Dázon Dixon Dialo: As you come to the mike, I want to remind you that this is a listening session for everyone in the room, so, it's your time, it's your three minutes. Stand in your truth, say what you have to say, say how you need to say it. But, perhaps you want to hold the others, if it's about something, or someone, or some entity. We're all people, we're all human, and we all have our frailties. So, when you say what you have to say, try holding my heart in your hand while you say it. I promise you, you'll be a little more conscientious of what you have to say feels like. Are we together?

All right, let's call Colonel Nicole Malachowski to the microphone for her time.

>> Nicole Malachowski: Is this thing on?

>> Dázon Dixon Dialo: It's not on.

>> Nicole Malachowski: It's on now? Great. Good afternoon, and thank you for the privilege to provide comment. My name is Nicole Malachowski, I'm an active duty colonel in the United States Air Force. I am here in my personal capacity, as a patient advocate, my comments are not intended to represent the Department of the Defense, or the air force.

I've served over 21 years as an officer, and a career fighter-pilot. In 18 days, I will be permanently, medically, retired from the career I love. I was found unfit for duty, due to the damage, and ongoing effects, of neurological tick-borne illness. My illness began in 2012 when, as the commander of an F-15E Fighter Squadron, I began experiencing rapid onset of multi-systemic symptoms. Repeated doctor visits yield no answers, no diagnosis, no treatment, nothing. Just over a year ago, I suffered from intractable pain, insurmountable fatigue, cognitive disfunction, and major problems with my speech, and short-term memory. I endured disorientation, confusion, anxiety, and even moments of temporary paralysis. I was unsafe to be left alone, I could not play with my children, care for myself, or interact with my husband, who had to be both caregiver, and single parent, during the worst of my illness. There were times I would have welcomed death. I thought I was tough, as a combat-proven fighter pilot. But, tick-borne illness destroyed me, brought me to my knees, and ruthlessly broke me.

It would be 1,525 days between my first doctors visit, and my accurate diagnosis. Often, I was told I was just suffering from stress. I felt patronized, discounted, and dismissed. I saw over 20 doctors, military and civilian alike, across eight specialties, and received three misdiagnoses. By sheer luck, I was finally able to be seen at the Dean Center for Tick Borne Illness in Boston, Massachusetts. They are the only reason I am here today, the reason I am able to, once again, stand, read, and speak.

Since my diagnosis, I have reviewed my own medical record many times, and I'm profoundly troubled that other service members, military family members, and veterans, may be enduring similar, unnecessary suffering. I am deeply concerned about the impact of these tick-borne diseases on our military. We are a high-risk population for encountering countless diseases, and

I would like to add special emphasis on Borrelia, and Bartonella. The tax payers of America invested tens of millions of dollars in my training. They are not getting the return on investment they should have. This is a health of the force issue, this is a military readiness issue, and this is a national security issue.

My doctors, civilian and military alike, were woefully uneducated about the breadth of tick-borne diseases, and how they present. The accuracy of diagnostic tests are abysmal, treatment options are inadequate. The entire life-cycle for a tick-borne disease patient is appalling, from prevention, to diagnosis, to treatment, to recovery. I will have spent over 21 years serving my country. Every day, I was measured and held accountable to the highest, strictest, standards of professionalism. That's as it should be.

The Departments of Defense and Veterans Affairs need to answer to the same level of accountability in their care of service members, veterans, and military families, with regard to tick-borne disease. I firmly believe they are uniquely suited to take an impactful leadership role in this area. Let's empower and resource them to do so, let's them lock their full potential. Now would be a great time to drastically increase funding to the congressionally directed medical research program for tick-borne disease. This working group has the opportunity to harness the rapidly evolving science in a way that joins forces with clinicians, and patients. You have my full support, and encouragement. Thank you.

[applause]

>> Dázon Dixon Dialo: Thank you. Thank you so much Colonel, and thank you for your service. Let's welcome Olivia Goodreau. Olivia?

[applause]

>> Olivia Goodreau: Hello. My name is Oliva Goodreau, and I am 13 years old, and am from Denver, Colorado, and I have Lyme disease. I have had Lyme disease, for half of my life, and I do not remember what it feels like not to be sick. The summer in-between my first, and second grade year, when I was seven, I was bitten by a tick in Missouri, on vacation. We did not see the tick, and I did not have a bullseye rash. When my second-grade year began, I started having body aches, brain fog, headaches, tremor in my right hand, I couldn't hold up my head, my legs would go numb, or burn. I had balance problems, light and sound sensitivities, and I started blacking out. My body felt like wood, and it was very hard to get out of bed.

My parents took me to over 50 doctors. I had MRI's, CAT scans, Spinal Taps, EKG's, liver biopsy, under and lower endoscopy. I had my adenoids removed, and over 100 blood draws. I spent a week in the hospital, and was in and out of the E.R. I was told I needed to drink more water, then I was misdiagnosed with Wilson's Disease, and told that I would not live past the age of 40. Then, when the DNA test came back, saying that I did not have Wilson's Disease, I was asked if maybe I was making this up.

January 29th, 2013, my 51st doctor finally diagnosed me with Lyme Disease. This doctor put me on 30 days of antibiotics, and said that I would be back to normal. By the fifth day of being

on the antibiotics, my parents said that they had seen the twinkle in my eye that had been missing for 18 months. I felt much better, and my third-grade teacher called my mom, and said, "I just met Olivia for the first time, and she is really funny." And, they both started to cry.

Unfortunately, after my 30 days of antibiotics were over, all of my symptoms had come back. My parents knew that they needed to find a Lyme specialist. For three years, I bounced around to different Lyme doctors in Colorado, but I was not getting better. My 54th doctor, is Doctor Richard Horowitz, with his M6 model, not only do I have Lyme Disease, but he diagnosed me with Bartonella, Barbitsio, relapse in fever, POTS Syndrome, low immune globin's, and anti-one trip zone deficiency in my liver. This is all from one tick bite that I never saw, and never had a rash, and 53 doctors missed everything. What second grader would make up a tremor in her hand, blacking out, and not being able to hold up her own head? While my friends were on spring break, I had a liver biopsy, spinal tap, and hundreds of tests that I did not need.

I read a story about a single mom with an eight-year-old son, who had Lyme Disease, and how the mom gave up their apartment, and was living in their car, so her son could get his Lyme Disease medication. After reading that story, I knew I had to do something to help these kids with Lyme Disease. So, on January 18th, 2017, I launched the LivLyme Foundation. I have raised \$288,000 for kids that cannot afford their Lyme medication, and for scientists, and their research, for better tests, better treatment, and to find a cure for everyone that is suffering from Lyme disease. Since January 18th, we have had 41 families, from 22 different states, apply for grants. The children are ages four to 20, with four families having three, or more, kids with Lyme Disease.

This Saturday, I will be announcing the 10 families that will be receiving a grant from the LiveLyme Foundation. This has been really hard, because I wish I could help all of these families and their kids. I have already given \$75,000 in research grants to Dr. Sapi, at New Haven, Dr. Zhang, at Johns Hopkins, and Dr. Rajad is at Stanford. My next grant will be going to Dr. Lewis at Northeastern. Having met, and toured, all of these scientists' Lyme Labs, which I learned how hard they, and their team, are working for the Lyme community. These scientists give me hope that we will have better treatment, and a cure, in the future.

So, I am here today to represent all of the children that are told that they are making it up. I am here to represent all of the people that are sick with Lyme Disease, and that cannot help themselves. I am here to represent all of the people that have lost their savings to help their loved ones with Lyme Disease. And, I am here because if a 13-year-old girl from Denver, Colorado can make a small difference in the Lyme world, think of what this panel of experts can do. Thank you for your time.

>> Dázon Dixon Dialo: Thank you, Olivia.

[applause]

Thank you so very much. Let's now hear from Amy Fitzgerald. Welcome, Amy.

>> Amy Fitzgerald: Thank you for allowing me to speak. My name is Amy Fitzgerald, and I've been living with Lyme Disease for 22 years. I was undiagnosed for the first 15 years of my life, when -- first 15 years, and was told I had Ankylosing Spondylitis, and then Fibromyalgia, even though I didn't meet the criteria for either diagnosis. I cannot recall if I was tested during this time for Lyme Disease.

My story is that I woke up one morning as a 24 year old, and could not get out of bed. My legs were paralyzed. I was in a wheelchair briefly, and then I moved on to crutches for mobility. I could not weight bear on my legs. I had pain in my joints, my back, my hips, I couldn't move my neck, my eye flared up, and I was diagnosed with Iritis. I had to sit in my bed, in the dark, as I was sensitive to light. I couldn't drive, I couldn't go to work, and I was 24 years old. I suffered from chronic fatigue. I lived this way for 15 years, going to doctor, to doctor, to doctor. At one point, I thought I was dying. Many times, I was told the pain was in my head, and I was told I would never run again.

When I was 39, on Thanksgiving Day, I was tired of being sick, and tired. I decided to try and run, and it was a very slow start, run-walk. But, I pushed myself for five miles, with my husband by my side. I continued to run, walk, and train for my very first long-distance race, a 10-miler. I had never felt better as the weeks passed. Remember, the doctor's told me I would never run again. They told me to rest. The pain slowly started to disappear, and I put away my crutches, although they still sit in my room, but I haven't used them for quite a while.

When less than a year had passed, and I developed pain in my wrist, and elbows, and I was so tired. I went to an infectious disease doctor, who tested me for Lyme Disease. My tests show I had a past infection, and currently have positive antibodies showing current infection of Lyme Disease. I was perplexed, because I had never been treated for Lyme Disease, and I didn't remember being bit by a tick, or having a bullseyes rash, currently, or in the past. It took two months of antibiotics to heal my body, of my Lyme Disease symptoms. I ran my first marathon, the Marine Corps Marathon, and shortly after finishing my antibiotic treatment. It is still my personal best marathon time, after running over 20 marathons, and ultra-marathons, including the Umstead 100-miler, who I raise funds for, for Nat Cap Lyme.

Two years later, I developed debilitating pain in my ankle bone. I researched different causes, and one thing that stood out in my research, was the pain could be caused by Lyme. But, I was healed from Lyme, I took those two months of antibiotics. I requested my doctor test me for Lyme, and my antibiotic blood test came back with the same exact results as it was two years prior. She called, and told me I have chronic Lyme Disease, which is kind of unheard of in the medical world. I was prescribed two months of antibiotic treatment.

This is when I dove into my research, and put the puzzle pieces together, and made the realization that I've been living with Lyme Disease since that terrible morning I woke up, and I wasn't able to walk. My life forever changed, as I knew it. And, today I still live with chronic Lyme, and recently had a relapse this summer. I want to introduce my daughter, Kaitlyn Fitzgerald, so, she'll talk about the pediatric side. Thank you.

[applause]

>> Dázon Dixon Dialo: Thank you, Amy. Thank you for sharing your story. Kaitlyn Fitzgerald, please join us at the mic.

>> Caitlyn Fitzgerald: Hello everybody, I'm Caitlyn Fitzgerald, and I'm 14 years old. My Lyme story is, I've been experiencing symptoms for as long as I can remember. Which include joint pains, muscle spasms, and headaches. But, there are also a lot more that I didn't realize weren't normal, because I thought they were, you know, not out of the ordinary. So, as you saw before, my mom has had Lyme Disease for a very long time, and since I've been experiencing these symptoms for a very long time, I've -- she's wondered if she had passed it on, through utero.

So, when we went to the doctor, my mom would always mention my headaches. They told me I was dehydrated, and I needed to drink more water. But, I've [laughs] been drinking lots of water, and bringing water bottles with me to school every day, so that was a little weird. And, the doctors always called these pains that I had 'growing pains', and I would just stop getting them eventually. But, here's the thing: I actually still have them, and they're much worse than they were before.

One morning, when I was around seven, I woke up, and I couldn't put any weight on my left leg. My knee was basically paralyzed, and my mom took me to the Urgent Care center, and they ran a bunch of tests, and they concluded nothing was wrong with me, which was concerning. The next morning, I woke up, and I was fine, but one of the tests they didn't run was the Lyme test. And, after my mom found out she had Lyme, she did a lot of research, and she got my siblings and I tested, since we like to play outside a lot when we were younger. And, I came back positive for Lyme, and my mom asked the pediatrician for me to have a month of antibiotics. After I got my antibiotics, I felt great, I didn't really have any symptoms. But, after a couple months, they came back, along with a lot more, including nerve sensations, my muscles are wonky [laughs], anxiety, and sight hallucinations, and many more.

When I first told people I had Lyme Disease, I actually didn't really know what it was, and neither did my friends. One of my friends actually said, "Isn't that the disease that just makes you really tired?" And, I thought that was an interesting point to bring up.

So, actually, this summer my mom brought me back to the pediatrician -- it was a different doctor this time. And, we told her what was going on, and how my symptoms have gotten worse since I got treated. And, she said she wasn't allowed to treat me, or give me anything, because she didn't want to get in trouble, and she didn't want to do anything she shouldn't do. Which, is understandable, but the problem is, I'm still sick, I still have symptoms, and it seems that there's nothing they can do about it for me, which, also, is concerning because I can't exactly get better. And, I have pains every day, I have brain fog, it's hard to focus in class, and there's not much I can do about it. And I know there's a lot of other people out there like me, who are experiencing the same thing, and there's nothing they can really do about it either.

So, I'm really excited that I was offered the opportunity to come here today, I found this an amazing experience, to come and listen to what you guys have to say. Thank you.

[applause]

>> Dázon Dixon Dialo: Thank you, Caitlyn. And, if I may, Caitlyn, in terms of how you're feeling every day, and in terms of what the future looks like, you are doing something. You've done a great thing here, today, and I thank you.

[applause]

Let's welcome to the mic, Jill Auerbach. Jill.

>> Jill Auerbach: Hello, and thank you. We need gold standards serology for all tick-borne diseases, two, we need cures to suffering. Three, tick research to stop ticks, and disease. Funding -- fourth, funding commensurate with tick-borne diseases. The last two, we need to accomplish.

All of us -- all of us have a dire need to include tick research as a critical part of the solution being derived by this work group. Yet, no tick scientist was included. The ability for the HHS Secretary to include that is stated in section 26-G2. Quote, "Other individuals whose expertise is determined by the secretary to be financial to the functioning of the working group" end quote.

What we have, is a huge environmental -- tick problem, which was first noticed in the Connecticut area. It has been allowed to spread, unabated, for 44 years, because of the lack of government funding, and attention. Lyme is now in about 50% of the counties in the United States, that's not including the other tick pathogens, and tick species. All have increased, and spread like wildfire. The societal cost of Lyme Disease alone, is about \$3 billion, while NIH funding is only about \$24 million, and CDC about \$10 million a year. Does this make any sense?

Ticks and mosquito vectors infect us with voracious pathogens. In the U.S., tick-borne disease outnumbers mosquito disease by about 80-to-1. But, funding is in the reverse. Until the tick population is reduced, and the tick ability is blocked from being able to transmit pathogens, the scourge of Lyme, and other tick-borne diseases, will continue to march across the USA, infecting, re-infecting, and co-infecting us, our children, our pets, and the critters that spread them. We must protect our future generations; these children should not be getting sick.

The problem has grown way beyond just one disease, and other fatal, hemorrhagic, encephalopathic tick-borne diseases are certain to reach our shores. A patch for Lyme disease is not a solution for the environment. Tick research scientists hold the most potential to bring about fruitful solutions. About 40 prestigious scientists join Tick Research to Eliminate Disease scientist coalition, TRED, in support of what I said. That should be enough to convince everyone of the critical importance of this long-neglected field.

Just one example, transgenic mosquito research is making great strides. I ask, why hasn't there been any transgenic research on ticks started? I urge the secretary to add tick scientists to this work group, and challenge you to include this as critical part of your discussions. The time is now.

I add two quick items. Disturbing, is that missing Steven Wycell, tick researcher, and basic scientists, such as Monica Embers. You must -- also, you must discuss a stop-gap measure, which could be Nucatone. Food great to humans, kills mosquitos, and ticks, but not honey bees. CDC testing demonstrated that a soap wash caused infected ticks to drop off of mice, killing 85 percent of them, no mice were infected. Since most tick-borne pathogens transmit in over 12 hours, a simple nightly shower, or bath, could prevent many diseases. Simple, safe, inexpensive. Better than tick checks. By the way, it's being funded by the CDC for mosquitos. Thank you, very much, for your attention.

[applause]

>> Dázon Dixon Dialo: Perfect. Thank you so much, Jill. Next up, we have Erica Keys-Land.

>> Erica Keys-Land: Hello, thank you so much for the opportunity to address you this afternoon. I've also submitted written comments for the record, but I'd like to use this opportunity today, to share with you my personal story, as well as my suggestions for the mission of the working group.

Having worked for 13 years as an attorney at the Department of Health and Human Services, Office of Chief Counsel for the Food and Drug Administration, I wrote, and reviewed, drug regulations, and also prosecuted those who failed to follow them.

However, I'm here today as a Lyme Warrior, as I've been battling Lyme Disease myself, for six years. I never saw the classic bullseye rash, and I never had a positive Western blot test. My symptoms started with joint pain, and brain fog, which got progressively more debilitating as I, like so many other Lyme Warriors, went searching from doctor to doctor, and found no answers. Finally, I tested positive for Lyme through a clinical diagnosis, from my wonderful infectious disease specialist, Dr. Joseph Jemsek. Two of my children have Lyme disease. My son had a bullseye rash, which was misdiagnosed as ringworm. He contracted Lyme, by the way, while living in New York City.

We all know, regrettably, that the new data shows that Lyme Disease is an unreported illness, and at least six times more common than HIV and AIDS. Thus, I think there should be an HIV, and AIDS style Manhattan Project to combat this serious pandemic. My suggestions for your working group are one, revoke the archaic, and ineffective IDSA Lyme Guidelines, and establish new ones. Next, establish a new standard for Lyme Disease testing. Third, review the evidence for the existence of chronic Lyme Disease. Come up with a new name, if you must, but most importantly, publicly acknowledge that the scientific evidence proves that Lyme Disease does, in fact, persist.

Make a public health announcement, so that those of us that are affected do not have to fight this silent battle with our team of scientific-based doctors, and with insurance companies. Once you publicly acknowledge the chronicity of Lyme Disease, then internists, rheumatologists, all doctors around the world, will stop looking at us like we're crazy. Furthermore, you might even save the lives of so many people who indeed have Lyme, but might be misdiagnosed with ALS, and M.S., Fibromyalgia, chronic fatigue, and so many other diseases that are overlooked.

Fourth, conduct further trials of antibiotic therapy, or other alternative forms of treatment, such as stem cell therapy, and also encourage pharmaceutical, and other alternative medical industry participation, using the best of both eastern, and western, medicine. Fifth, stop putting forth efforts, and scarce resources, into the failed Lyme vaccine concepts, because there's been more than one.

Thank you so much for the opportunity to speak today. If you need any more Lyme patients, I'm here, would love to help out. One more thing, Dr. Jemsek, who's here today, if there's any way you could get him up on the mic to say a few words today, I would -- I'm sure he'd be a benefit to this process. Thank you so much.

[applause]

>> Dázon Dixon Dialo: Thank you, Erica. Let's now hear from Kristina Bauer. Kristina, take your place at the mic, please.

>> Kristina Bauer: Good afternoon. Thank you all for having us here today, and coming yourselves. My name is Kristina Bauer, I am a physician facilitator for the North Texas Lyme group, owner of Yoga Center G-spine Wellness Center for 12 years, and mother of four, ages eight through 14.

I caught Lyme Disease 35 years ago in Illinois from several tick bites, playing in the woods by my house. I've seen countless doctors, and had many different, inaccurate diagnoses. I treated GI Lyme, misdiagnosed as Chromes Disease ineffectively for 26 years, following ulcers, and, as well, an obstruction. Could have killed me. Gastroenterologists would recommend immuno-suppressants as my only line of treatment, many times. This type of uneducated recommendation by the GI community could cause the Lyme to take over my immune system. In contrast, I started an antimicrobial, and immune building stomach protocol five months ago, resulting in no more ulcers, pain, or inflammation.

I passed Lyme to all four of my kids, our children, during gestation unnecessarily, as research shows. The government knew Gestational Lyme existed back in 1985. I have the studies today, to talk about after this meeting, if you're interested in those. Some of my children, and I, have been bedridden in severe pain, had seizures -- my son on his seventh birthday, which we had to cancel his seventh birthday party because of that, lost the use of our body, and brain. One child was in four different schools by the second grade, due to undiagnosed illness causing severe learning difference. After treatment, he gets straight A's, and mom's so proud, and he has rebuilt his self-confidence. We have spent over \$100,000 on extended antibiotics, and other validated therapies, and successfully cleared four, of five, of us of viruses, Lyme and co-infections, but only for now, as it is lying dormant forever, once you get it.

\$52 million over 17 years of government grants studying infections have yielded no tangible benefits to Lyme patients. Therefore, I propose to you today, several things. Number one, anyone who denies persistent Lyme be banned from participating in the tick-borne disease working group.

[applause]

Thank you. Non-pharmaceutical therapies is number two, that are peer-reviewed and validated, need to be covered by insurance companies, so everyone has access to treatment that works. Number three, encourage the millions of cancer clinics across the United States, and the world, to integrate Lyme treatment that could provide an immediate ability to treat severely desperate Lyme sufferers, since Lyme affects the B cells, similarly to cancer. Number four, patients who have been bankrupted, and disabled by this disease require government sponsored medical care, to regain the capacity of productive -- being productive members of society. In July, after treating for five years, I've had a poor, and a pick line. I went to Germany, and received 10 million of my own blood cells -- stem cells, and have seen healthier days then since I was a child.

Number five, I look forward to the U.S. offering the use of auxologist blood stem cells to repair the damage from Lyme and Co-infections someday. Number six, and lastly, demand that doctors use the most current, and AMA approved, CME training online, written by Dr. Maloney, and are free on many websites, including txlda.org website. I'm hearing today we are forward thinking, so I'm asking to you, please update the link on CDC's website to NIH, which still hosts IDSA treatment guidelines with current science, not old science. We demand, and deserve better. Thank you for listening today.

[applause]

>> Dázon Dixon Dialo: Thank you so much, Kristina, thank you. Next up, Tim Lynagh. Tim. And, tell me if I pronounced that incorrectly.

>> Tim Lynagh: Lynagh, actually, you got that right. Yeah, I think I'm, kind of, a -- well, I feel like I'm in an awkward position, following all those heart-wrenching patient stories. And they were, I mean, I was close to tears, over there, at one time, myself. My name's Tim Lynagh, and I started working on Lyme when I was on -- working on Capitol Hill. And, then, when I left the Hill, I started to volunteer with the Lyme Disease Association. And, I'm not going to do a broad brush, or a broad take, on issues, but to address some specific issues related to surveillance.

Surveillance of both human disease, and tick vectors, is important, because it provides us an idea of risk, in terms of prevalence of exposure, and provides data necessary to estimate disease burden including both morbidity, and mortality, and financial cost to individuals, and society. Surveillance issues also have a major impact on the individual's ability to receive diagnosis, and treatment.

Now, as Gregg Skall had mentioned, significant attention should be paid to the Lyme Disease case definitions developed by CDC in collaboration with the Council of State and Territorial Epidemiologists. Case definitions constitute surveillance criteria, not diagnostic criteria. A history of surveillance case definitions for Lyme Disease since 1995 show them getting significantly more stringent. But, up until the 2017 iteration, they all contained the statement,

quote, "This surveillance case definition was developed for national reporting of Lyme Disease. It is not intended to be used in clinical diagnoses." Close quote.

Even before that language was dropped from the case definition, patients across the U.S. were refused diagnosis, and treatment by physicians who told them, "You do not meet CDC criteria." And, physicians who did treat were often subject to discipline. This is particularly relevant to those in the south, and Midwest, who have consistently been told they have little, or no, Lyme, in what are now called Low Incident States, a 2017 surveillance term.

The definition of high incidents, and its application in the case definition, make it almost impossible for any state that is not now classified as high incidence to become so designated. Tens of thousands of people over time had to travel across the country to high incident states, to receive care. Many have progressed to chronic disease, and been severely debilitated, when early diagnosis and treatment had been denied, based on surveillance criteria. And, now, the MMWR has even stopped reporting case numbers weekly, although Lyme has one of the highest reported case numbers in the MMWR. Only an annual total is now reported.

Access to care is dependent upon accurate surveillance, as is funding, since diseases with high numbers, and high disease burden are considered more deserving of funding. The \$40-\$45 million spent by the federal government, including CDC, NIH, and DOD's CDMRP, is inadequate to address Lyme, which can be demonstrated to be close to 400,000 new cases in 2015, based on 90 percent underreporting.

We also need to develop a more systematic, and comprehensive, plan for surveillance of human TBD's other than Lyme, and co-infections. As well as a comprehensive vector surveillance strategy. In a 2017 article, tick-borne zoonoses within the U.S. persistent with emerging threats to human health, Ben Beard, Christopher Paddock et al, described 12 major TBD caused by 15 distinct disease agents, by the 8 most common human biting exuding ticks in the U.S.

>> Dázon Dixon Dialo: Time.

>> Tim Lynagh: Six of the 15 pathogens were recognized in caught illness -- to cause illnesses, only within the past two decades. Thank you.

[applause]

>> Dázon Dixon Dialo: Thank you so much, Tim. So, now I'd like to call to the mic, Gill Lake. Gill.

>> Gill Lake: Thank you. I just wanted to point out that this panel here is dedicated to cognitive dissonance eradication, are we in agreement? You had a really good display up there, with the hands on the bible, but that is not a constitutional thing, you could have just as well had a constitution to put your hands on, it's all I'm going to say, thank you.

>> Dázon Dixon Dialo: Gill.

[applause]

And, I'd like to call to the mic, last but not least in the voices of this afternoon, Meghan Delaney. Meghan.

>> Meghan Delaney: Does this -- can I sit? I'm wondering if that's a -- oh, no -- [inaudible] okay. I don't trust my autonomic nervous system right now. So, I wasn't sure if I was going to make it here today, so I don't have anything prepared. This is really important to me, I'm here as a private citizen, but I've worked for the Department of Defense my entire career in the healthcare field. I'm not a clinician.

My story starts off a bit like a "House" episode. At 29 years old, I got off of a rollercoaster in San Antonio, Texas, and had what looked to be a heart attack. And, that didn't really make much sense to most people. I worked around a lot of physicians who knew me, and knew my work ethic, and knew who I was, and saw me deteriorate over the next few years, and scratched their heads. They all believed something was very wrong, but no one was quite sure what it was. And, because it manifested initially with me as cardiac symptoms, I was pushed through the system, I was seen all over the place, I was at Hopkins. It eventually moved into my nervous system.

Again, none of us knew exactly what was going on at the time, I lost the ability to walk, they started to think I had M.S. I was seeing rheumatology, neurology, cardiology. I ended up out at Cleveland Clinic four and a half years later, after now being on disability for six months. Didn't really get too far there, and, then, I ended up getting pulled out of my car on 66 unresponsive with another stroke, and as I was in the emergency room at Fairfax hospital, the doctor recognized me from my work with DOD, and international health, and asked me what DOD was doing for Ebola. As I was laying there [laughs], unable to move one side of my body, and unable to talk.

So, there's some irony here. I knew at that point, after four and a half years of this, and the complete deterioration, that I was going to possibly end up dead. I was, thankfully, able to see a Lyme specialist, who got me the right testing eventually. I want to make it clear that through the journey, there were doctors who truly believed something was very wrong, and they were more than willing to go through the process -- the lengthy process of submitting me for NIH rare disease programs.

But, before this all started, I had a bite on my leg, and I showed it to the doctors that I worked with, who are my colleagues. And, no one ever put two and two together. So, unfortunately, this has greatly impacted my life, and my family's life, I had to drop out of grad school, my career goals have completely changed. I'm here today -- I'm really happy to see what's happening. I'm a little concerned, and I'm hoping that this working group can help with the fact that I work with scientists, I work with clinicians, I know what they need to see, I know what they want to see, and I know they saw me happening, but I didn't fit their textbook, in what they learned in med school 30 years ago. And, I didn't fit the diagnostic criteria, and the blood work that showed up as results. But, they still believed something was very wrong. I'm hoping this working group can help highlight the fact to conventional medicine, and mainstream medicine, that this issue is

not case closed. We might not have all the answers, but don't write people off, and never look at this issue again.

The amount of money that has been spent on me through the medical system, and what I've spent, you know, a lot of this probably could have been addressed initially, and I never would have gotten to the place I'm in. So, thank you for being here, thank you for your time, and I really look forward to the progress of the working group.

[applause]

>> Dázon Dixon Dialo: Thank you, Meghan, thank you so much. For the brave, courageous, honest, direct voices and messages that are all so loving, that are all so strong, and that are all so determined to see things happen, and to see something change, please give a rounding, sound of applause for all of the voices we've heard this afternoon.

[applause]

This is what resilience to revolution looks like. Thank you all. What I didn't tell you, as I take my seat, turn this over -- back over to Dr. Wolitski, is that as a member of ACT UP, and as a part of the women's HIV Aids movement. Prior to 1994, that was more than 13 years into the epidemic, already with hundreds of thousands of people already dead, or dying, including women who were sick from day one, and had never been diagnosed. There are women who died, never knowing why, and families who were never able to say why, and it took us three plus years of a determined, hard fought, ugly, awful fight just to be included. Because, we knew that women were experiencing things differently. And, in 1994, the Centers for Disease Control finally expanded the definition of what was then known as AIDS, to include women, and children, and more homeless people than they had before. And, more poor people, who were not getting those diagnoses.

We then went on, because that doesn't end the fight. We needed more research, to know which drugs work best, were there gender differences, were there any other differences, and could we do better with treatment? And, by the way, can't we do better with prevention? We're 37 years into this epidemic, and we're still fighting for those things, but we have so, so, so many wins, that we can count along the way. And, I'm telling you this, because I know that there's that high school chant -- I'm just going to say this, my high school -- my high school alma mater team just got the state championship stolen away from them in the state of Georgia, this past week. So, I can say, I believe that we will win. I believe that we will win, and I know that you will win, and that you will stop the suffering.

There's a man -- I used to call him my movement husband, maybe because he's really smart, and really good looking, but he doesn't know me, so I figured that might not be appropriate. So, I started calling him my movement muse. He's a human rights lawyer, he fights on behalf of juveniles in the justice system. He actually won the Supreme Court case to make it unconstitutional to sentence juveniles to life in prison. He's an amazing human being, and I heard him speak, and I read his book. And, he has these four tenants which I define as the most important pillars to sustaining social change, to sustaining the end result, and the fight, which is

always long, and seems unending, and how to count our battles along the way, when we do know we've won.

And, here are those four tenants, and I want to raise them, because I think that you have already laid out the foundation to sustain this work, and social change. Just based on Bryan Stevenson, author of "Just Mercy", director of Equal Justice Initiative. One, proximity. You have to be proximate to the issue. You have people on your working group, you have the voices of people in the room who are living, or have lived, the experience, and know the ins and outs of what you need to know of what this looks like, and feels like, and including those voices in the work that you are about to do. You are already getting proximate.

Two, change the narrative. Change the narrative. I've heard that there needs to be changes in the IDSA, that there need to be changes in how physicians identify Lyme Disease, and other tick-borne, and other vector related, I've heard that you might even need to change the name. Change the narrative, do not let the consistency of status quo stagnate what has to change in what you are looking to achieve.

Number three, you got to be willing to get, and make, other people uncomfortable. You got to be willing to step outside of your own comfort zones, speaking in public when you're not accustomed to it, joining boards that may require you to do a little bit more work, voluntarily. All kinds of things, that you might not be as comfortable talking about, or getting involved in. Because, I believe that as long as you're comfortable, you aren't trying to change anything.

And, the last one, is protect the hope. You have to believe every day that you are doing something that's going to make a difference, and that you're going to win. And, I truly believe that you are well on your way, and he doesn't know you all either, maybe, but I have a feeling that Bryan Stevenson would be just as proud of you, as I am.

And, so, thank you so very much for including me in your process today, and for trusting me to facilitate the sound of your stories. Thank you very much.

[applause]

We have a thank you to add. So, this is a sound of appreciation?

>> Jill Auerbach: Yeah. I want to thank all of you for your dedication, and to the hope that we will find a difference for the future generations. I also want to bless, and thank, the doctors who maintained their Hippocratic Oath by not deserting the patients, by treating us, when I thought my life was completely over. I had a doctor who did not desert me. I bless them for their dedication, and for their willingness to even stand up, and be prosecuted, and everything else, for doing what they knew was right. Thank you for giving me my life back.

>> Dázon Dixon Dialo: Thank you.

[applause]

>> Jill Auerbach: And, all the others.

>> Dázon Dixon Dialo: And, all the others. So, you just stole my thunder, I had your last little bit of appreci-love exercise. That's where, you know, we appreciate, love each other at the same time. But, I think you've taken care of that for me very well, Jill. Gratitude is what keeps us moving, and I want to show mine, by handing over the mike to Rich Wolitski. Rich, thank you for inviting me, and for having me here today.

>> Richard Wolitski: Thanks, Dázon.

[applause]

I appreciate so much, for making time to do this, between your travels back and forth between Atlanta, and South Africa, and the work that you do is truly inspirational.

So, I'm going to, before I say anything, ask if Kristin [phonetic sp], and John [phonetic sp] want to add their comments to the end of it, and then we're going to talk a little bit about tomorrow. And, then, we'll be done ahead of schedule.

>> John Aucott: Takes a lot of courage for people to stand up, and it was really inspiring to see that, and I think that's what we needed to hear, so I really appreciate everyone's input, and for those of you, you know, attending virtually, we appreciate you as well, and your time that you spent today. And, you know, listening's important, and that's what we've done today, so, we're on the right track.

>> Kristen Honey: Yeah, just, huge gratitude and thanks for all those who stood up and shared their story, and all those who are still living them. And, we will follow the four pillars, and not lose the hope. And, I just want to reiterate before we close and go into tomorrow, that this is an ongoing process, and a beginning, and decisions here, we can revisit them. We have 13 members now, we'll have 14. We're all people, and the decisions we make on this tick-borne disease working group if we made them, we can unmake them, or remake them, or morph them, to fit the needs. So, please think of this as an ongoing dialogue, and your contributions will shape the future, and we'll go into some logistics, how to do that next.

>> Richard Wolitski: Thank you. So, I'll just state the obvious, as well. I mean, it's incredibly powerful, to hear directly from people about their experiences, and, you know, so much to me. Just brings back all these memories back, you know, in the late '80's, early '90's, before we had effective HIV treatment, and just remembering what those days were like. And, the one thing that, just always surprises me when I look back at them, was not that we were depressed, and scared all the time, but that we had hope. And, we just always had this sense, that if we just fought a little harder, worked a little longer, and just kept on going, kept on trying, that somehow things would be better. And, they have gotten better -- they're where they need to be, or where they could be, but they're better.

And, I just, kind of, carried that hope with me, for all of you, for all of us, in the work that we're doing here, that there's a tremendous opportunity. People have said it a number of different

times, the time is now, and I'm confident that we're going to do you proud, and that we're going to do a great job with this process. Is it going to be perfect? No. Will there be improvements that can be made over time? Yes. It's going to be a process.

And, I think, that's, sort of, you know, one of the things, you know, about life in general, that, you know, you really learn the most when you mess up. When you don't get it quite right, and you go back to it, and you try again. And, you work on it until you get it right. When you really mess up, is when you don't get it right the first time, and you don't admit that you didn't get it right, or you just say, "I'm done, it's too hard, it's not going to work for me."

And, so, I think, we've got some heavy issues that have been dealt with for a long time, by a lot of people, and if they were easy, they would have been solved already. And, so, I think it's that commitment that the members of the working group, the commitment that all of you here in the audience, and all of you, who have taken your time at home, or at work, wherever you are, to watch this on the internet, to build the community that makes this work possible, and that will hopefully, ultimately, make it sustainable, as Dázon has mentioned.

So, I really just, kind of, you know, want to thank you all for being here, and for approaching the issues, and the work in the way that you have. This has been -- just had great interactions with people, who have really, you know, taken the time to educate me, share their stories, and I appreciate that.

So, tomorrow, we have a long day. We're going to be starting the meeting promptly at 9:00 am. The doors here, will open at 8:30 am, and, so, it will be the same sort of system as yesterday. Going through security, encourage you to be early, as so many of you were today. So, we got a good start, right on time, which is unusual for these types of meetings. So, we're going to start off the morning by hearing from some additional organizations, be hearing from some provider organizations, and also hearing from public health organizations after that.

And, then, it's going to shift into -- really, kind of, talking about the work, and talking about, what is it that the working group has to do, and how's it going to do it? And, that's really, kind of, tomorrow is, you know, after we hear from the professional organization -- it's about the workplan, and it's about figuring out the work that needs to be done, it's about timeline, it's about the task, and breaking it down, and figuring out how we together go forward on this.

And, so, with that, I think I will turn it back to you, because I can't end the meeting -- you have to adjourn it [laughs].

>> John Aucott: Seconds? All right, all in favor of adjourning today's meeting session say, "Aye."

>> Multiple Speakers: Aye.

>> John Aucott: Opposed? The meeting's adjourned, thank you very much.

[end of transcript]