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THE TICK ACT: AN URGENT PUBLIC HEALTH RESPONSE TO TICK-BORNE DISEASES

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THE TICK ACT: AN URGENT PUBLIC HEALTH RESPONSE TO TICK-BORNE DISEASES

THURSDAY, SEPTEMBER 5, 2019

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The Committee met, pursuant to notice, at 10:06 a.m., at the University of Maine Cooperative Extension Diagnostic and Research Laboratory, Orono, Maine, Hon. Susan M. Collins (Chairman of the Committee) presiding.

Present: Senator Collins.

OPENING STATEMENT OF SENATOR SUSAN M. COLLINS, CHAIRMAN

The CHAIRMAN. Good morning, everyone. This official hearing of the Senate Special Committee on Aging will come to order. First, let me welcome everyone who is here today.

Lyme disease and other tick-borne diseases have soared in Maine and across the country during the past 15 years. Many of you here today have had firsthand experiences with the devastating consequences of tick-borne diseases. I would like to take just a moment to recognize Susie Whittington, whose mother, Lyn Snow, a well-known artist who captured Maine so beautifully, tragically died in 2013 from the deadliest tick-borne disease known as "Powassan." Thank you so much, Susie, for being here with us today.

My thanks also to the University of Maine Cooperative Extension's Tick Lab for hosting this hearing. I just toured the lab, and I was so impressed with the extraordinary research and work that is going on here. I saw firsthand how its outstanding work is advancing our understanding of the diseases that ticks carry and how the employees of the lab are working every day to protect Mainers.

They also do a host of other important work in this lab, and it was wonderful to learn more about it, so thank you, Jim Dill, for arranging for the tour and for all you did to welcome us.

In Maine last year, there were approximately 1,400 new cases of Lyme disease, nearly double the number of cases as 2010, as we can see from this chart. Listen to this fact: The incidence of Lyme disease in Maine is the highest in the country, at 107 cases per 100,000 Mainers, which is 10 times higher than the national average. I was talking with President Joan Ferrini-Mundy here today and talking about the work that the lab is doing and the university is doing and how incredibly important it is, and it includes this tick removal kit, which the lab will make available to anyone who wants one and which our wardens and other State employees who are working outside, like Inland Fisheries and Wildlife, can use.

Other tick-borne diseases are also on the rise. For example, anaplasmosis, related to rickets, has increased by more than five-fold. While ticks do not discriminate and the diseases they carry affect Americans of all ages, tick-borne diseases disproportionately affect people over the age of 65, and that is why, as Chairman of the Aging Committee, I thought it would be appropriate for us to hold this hearing.

From children to seniors, far too many Americans with Lyme disease experience a complex diagnostic odyssey that takes months or even years. One of my nieces, Catherine Collins, contracted Lyme disease and had a very difficult time getting an accurate diagnosis. She went on to get Lyme disease two additional times, but at least in those cases she knew what to look for. Regrettably, her story is not at all unusual, as we will learn from our witnesses.

In addition to the physical and emotional toll that Lyme disease can impose, it is also expensive. Medical costs of Lyme disease are estimated at $1.3 billion per year. When accounting for indirect medical costs, including the loss of work, the annual costs balloon to $75 billion per year.

A correct and early diagnosis can reduce costs and improve the prognosis, but we have a long way to go. When HIV became a public health crisis, a gold standard for identification and treatment was developed within 10 years. Lyme disease was identified more than 40 years ago, yet there still is no gold standard for treatment. Existing prevention, education, and diagnostic efforts are helpful but remain fragmented. It is time for us to unite in the fight against ticks.

Earlier this year, I introduced the bipartisan bill with Minnesota Senator Tina Smith and my Maine colleague, Senator Angus King. It is called "The TICK Act." "TICK" in the name of our bill stands for "Ticks: Identify, Control, and Knockout." Through a uniform and unified approach, this legislation would arm local communities and States with the resources they need for prevention, early detection, and treatment of tick-borne diseases.

The TICK Act would apply a three-pronged approach to tackle Lyme and other tick-and vector-borne diseases. First, it would establish an office to develop a national strategy to prevent tick-borne diseases. Second, the bill would reauthorize the Centers for Disease Control Regional Centers of Excellence in Vector-Borne Diseases that have led the scientific response to fighting ticks. Finally, the bill would establish grants to support State health departments' efforts to improve data collection and analysis, early detection and diagnosis, treatment, and public awareness, and that indeed is one of the purposes of our hearing today, to increase public awareness.

We are very fortunate to have with us a truly extraordinary group of witnesses, including national, State, and local experts. I also am very pleased that we have two individuals who are going to share with us their personal experiences with Lyme disease. These individuals will give us their insights on what it has been like to have Lyme disease and will share their journey and their advocacy efforts with us. They are Paula Jackson Jones and Christopher Philbrook, and I will introduce them in more detail in just one moment.

We will now turn to our witnesses.

First, I am pleased to welcome the Director of the Division on Vector-Borne Diseases at the Centers for Disease Control and Prevention, Dr. Lyle Petersen. A leading international authority on tick-borne diseases and on vector-borne diseases more generally, Dr. Petersen has worked through epidemics in the past from HIV to Zika. Today he is leading the fight against Lyme.

Dr. Petersen, we are really delighted that you have traveled so far to be with us today, and I want to note his personal effort to rearrange his schedule because his daughter is getting married this weekend.

He really has made an extraordinary effort to be with us.

Next, we will hear from Dr. James Dill, who is also our gracious host here at the University of Maine Cooperative Extension Diagnostic and Research Lab. Dr. Dill serves as the lab coordinator as well as the pest management specialist. His leadership on tick-borne diseases is well known in Maine, both as a scientist and as a policymaker, since he serves in the State Senate.

Next, we will hear from Dr. Sean McCloy, the medical director of the Integrative Health Center of Maine, in Cumberland Foreside. Dr. McCloy brings a background of public health and a wealth of knowledge in providing care to patients with tick-borne diseases.

I am very pleased that Paula Jackson Jones, an extraordinary advocate who survived Lyme disease and founded a nonprofit organization, the Midcoast Lyme Disease Support and Education Association, and she will be testifying today. Her work has been recognized in Maine and nationally. The Union Fair recognized her organization with an award last month, and she has also been honored to be chosen as a Point of Light, a national recognition for her service for others. You may remember that that organization was first started by President George Bush.

Finally, we will hear from a personal friend and former staffer of mine, Christopher Philbrook, who will share his personal struggle with Lyme disease. I have known Chris for years and how well I remember when he was working with me and trying to figure out this bizarre set of symptoms that he had. He will describe how this disease has affected his life, and I am very thankful for his willingness to be public with his story.

I want to thank all of you for joining us today. We look forward to hearing your testimony, and Dr. Petersen, we will start with you.

Before we do that, I want to run one brief advertisement here for the lab.

I want you all to pick up the tick removal kit that you will find on your chair, and this will be very helpful to you if you find, after walking in the woods or gardening or hunting, this being outside, that you have picked up a tick, and it will tell you what to do, and the University of Maine does an extraordinary job in identifying ticks and also telling you whether or not they carry a pathogen.

Dr. Petersen, thank you for being here. Please proceed.

STATEMENT OF LYLE PETERSEN, M.D., MPH, DIRECTOR, DIVISION OF VECTOR-BORNE DISEASES, NATIONAL CENTER FOR EMERGING AND ZOONOTIC INFECTIOUS DISEASES, CENTERS FOR DISEASE CONTROL AND PREVENTION, FORT COLLINS, COLORADO

Dr. PETERSEN. Good morning, Chairwoman Collins. I am Dr. Lyle Petersen, Director of CDC's Division of Vector-Borne Diseases. Thank you for the opportunity to testify before you today on our efforts to protect the U.S. from the growing threat of vector-borne diseases, and tick-borne diseases in particular. We appreciate your continued commitment and support in this area. I lead our agency's efforts to research, prevent, and control viruses and bacteria spread by mosquito, tick, and flea vectors. These vectors transmit over 100 pathogens known to infect people, including West Nile, Zika, Lyme disease, and plague.

We recently examined trends in vector-borne diseases and found that the reported cases in the U.S. tripled from 2004 to 2016. During this same period, tick-borne disease cases more than doubled, and the U.S. experienced several mosquito-borne outbreaks, including Zika. In 2017, reported cases again increased for all nationally notifiable tick-borne diseases.

We are particularly concerned about vector-borne diseases in Maine. Reported cases continue to rise steadily over time, with more than 98 percent of them being tick-borne. On a population basis, as Senator Collins noted, Maine had the highest incidence of Lyme disease in the Nation, with more than 1,800 cases of Lyme disease reported in just 1 year. Maine also had the second highest incidence of anaplasmosis, second only to Vermont. These statistics are of great concern to us, and we are working closely with the Maine CDC and academic institutions to address this growing threat.

Why are we seeing more diseases than ever before? There are at least three major factors at play.

First, we know more about vector-borne disease pathogens than ever before. In the last 13 years, 9 new vector-borne pathogens were identified in the U.S., including Zika and seven new tick-borne pathogens.

Second, travel and trade are moving more pathogens and vectors around the world. Zika virus was an example of the impact that travel can have on the spread of disease. The U.S. had more than 5,000 reported cases in 2016 of which most were in travelers returning from infected areas.

Third, existing vectors continue to expand across the U.S. For example, the ticks that spread Lyme disease and other tick-borne diseases are now found in 1,500 U.S. counties covering 43 States. This marks a 45-percent increase in the number of counties that have recorded these ticks since 1998.

We now have another tick that could pose a threat to the public's health. The Asian longhorned tick was first discovered in New Jersey in 2017 and has now been identified in 11 additional States. This tick causes massive infestations and transmits several vector-borne diseases throughout the world. To date, this tick has not been found in Maine; however, models suggest that Maine has a suitable habitat for this tick. State tick surveillance activities, funded by CDC, should allow for early detection if this tick arrives in the State.

What are we doing to address all of these threats? We know that vector-borne disease can be devastating to families in Maine and across the Nation. CDC is committed to addressing Lyme and other tick-borne diseases. We are improving diagnostics so that doctors can best support patient outcomes. We disseminate the best scientific information to health care professionals and the public and work with State and local partners to ensure that Lyme disease prevention and information are readily accessible.

We are grateful to Congress for their support in the years following Zika, which has enabled us to increase support for vector-borne disease prevention and control across 64 U.S. jurisdictions while providing enhanced support to nine States and one U.S. city at high risk for disease.

We know that there are still unmet needs. For example, many State health departments in the Northeastern U.S. like the Maine CDC have expressed concerns that they are hard-pressed to address both Lyme disease and anaplasmosis, especially because the incidence of anaplasmosis has more than doubled in the last 4 years.

CDC is committed to reversing the upward trends in vector-borne disease. However, it is clear that this will not be easy. There are no proven community prevention methods for the most common tick-borne diseases as well as many mosquito-borne diseases. Although we can control certain mosquito-borne diseases, current national, State, and local capacity is limited. Finally, there are no human vaccines for any vector-borne diseases found in the U.S.

We are committed to making strategic investments in promising new prevention strategies, including informing and supporting vaccine development and implementation, as vaccines become available.

Thank you again for the opportunity to appear before you today and for your support of our fight to protect the U.S. and its territories from the growing threat of vector-borne diseases. I am happy to answer any questions that you may have.

The CHAIRMAN. Thank you, Dr. Petersen.

Dr. Dill.

STATEMENT OF JAMES DILL, Ph.D., PEST MANAGEMENT SPECIALIST, AND DIAGNOSTIC AND RESEARCH LAB COORDINATOR, UNIVERSITY OF MAINE COOPERATIVE EXTENSION, ORONO, MAINE

Dr. DILL. Well, good morning, everyone, and welcome to the University of Maine, and thank you especially to Senator Collins for the opportunity to speak before the Special

Committee on Aging in regard to the increasing challenges associated with combating tick-borne disease here in Maine. As the pest management specialist for University of Maine Cooperative Extension and a State Senator in the Maine Legislature, I have had the unique opportunity to experience these challenges from both the political and scientific perspectives, but today I will speak from my university perspective.

Tick populations have undergone extensive range expansion over the past 50 years, particularly here in the Northeast. Multiple factors, including reforestation, changes in climate, and increased abundance of wildlife hosts such as rodents and white-tailed deer, have contributed to this surge. Maine is a heavily forested State with a largely rural population that spans four degrees of latitude and maintains a robust wildlife population. As such, we have witnessed a dramatic increase in the number of ticks, their geographic distribution, and the subsequent incidence of tick-borne disease.

This increase in tick-borne diseases has rapidly become a significant public health issue in Maine and throughout much of the United States. The incidence and distribution of these pathogens continues to increase, often resulting in severe health issues for those affected.

In addition to the public health threats associated with tick-borne disease, societal and economic costs have also had economic impacts. Of the roughly 13 tick-borne diseases identified in the United States, 5 have been found in Maine, including Lyme disease, anaplasmosis, babesiosis, Borrelia miyamotoi disease, and Powassan encephalitis. The primary vector of these pathogens, the deer tick or black-legged tick, has greatly increased in both population size and geographic range within the State. Furthermore, Maine faces significant threats related to invasive tick species including the lone star tick and, as just mentioned, the Asian longhorned tick, both of which can have serious impacts on the health of humans, wildlife, and domestic animals.

Combating these threats is an immense challenge that relies heavily on an integrated approach that includes investment in new medical treatments, diagnostics, and vaccines, as well as research into monitoring tick populations, reducing tick and host habitat, managing ticks and their wildlife hosts, and widespread educational outreach.

Maine has been fortunate to have a relatively long history of research and outreach on tick-related issues thanks to a collaborative network of private and public institutions. The Maine Medical Center Research Institute has been conducting research on ticks and vector-borne disease since the late 1980's and has emerged as a leader in the field. Maine CDC has taken a proactive role, combining epidemiology with widespread public outreach efforts to help minimize the spread of tick-borne diseases. Many States have stopped counting cases of Lyme disease due to the high burden placed on State health departments and have begun instead estimating their cases. These estimates can vary in their accuracy, thus affecting the regional and national rates of disease. Maine CDC is still counting individual cases, but as the burden continues to increase and funding remains limited, a transition to an estimation system also might be likely.

At the University of Maine, significant research is underway both in the School of Biology and Cooperative Extension. A primary goal of UMaine Extension is to explore ways to minimize the occurrence and spread of ticks and tick-borne disease in Maine. Understanding the shifts in tick population size and geographic range is critical in evaluating risk and targeting management strategies. UMaine Extension currently monitors tick populations through a public tick identification program and tick-borne disease screening program. Through these programs, Maine residents can send tick samples to the lab for identification and to test whether the ticks are carrying the pathogens that cause Lyme disease, anaplasmosis, and babesiosis. Additional pathogens are scheduled to be added to the testing program in 2020. A small-scale active surveillance program is also ongoing, in which ticks are actively monitored through field survey methods. Additional active monitoring of small mammal hosts is also ongoing. The information generated from these programs will allow us to track the distribution of ticks and tick-borne disease in Maine and to identify priority areas for targeting prevention and management strategies.

The University of Maine School of Biology and Ecology is currently investigating multiple avenues related to the ecology of tick-borne disease, including the environmental conditions that enhance disease transmission, the impacts of climate change and human land-use patterns on ticks, as well as the risks related to tick-borne disease in Acadia National Park and its potential effects on the tourism industry.

The public demands and political will to fight Lyme disease and other tick-borne diseases are strong in Maine; however, as with many rural States, the funding to wage such a battle is limited. Nonetheless, the people of Maine prioritized this battle in 2014 when voters approved a bond referendum to create the new University of Maine Cooperative Extension Diagnostic and Research Laboratory.

Following several years of intense planning and construction, the new lab opened in June 2018. This high-containment facility brings together research on animals, plants, and arthropods within one biosecure setting and has greatly enhanced the university's diagnostic capabilities. The construction of this facility has also broadened the university's collaborative efforts, facilitating collaborations between UMaine, Maine CDC, and the Maine Medical Center.

Through the work being done at UMaine Extension, the University of Maine School of Biology and Ecology, Maine Medical Center, and the Maine CDC, the State has a solid infrastructure in which to tackle the issues surrounding tick-borne disease. Historically, however, funding for tick-related research and particularly outreach and education has been a relatively low priority. The TICK Act will inject a much-needed investment into research and education and allow us to leverage existing infrastructure to fund novel approaches to monitoring and managing ticks and tick-borne disease.

Thank you again, Senator Collins, for the opportunity to speak today, and I welcome any questions.

The CHAIRMAN. Thank you very much.

Dr. McCloy.

STATEMENT OF SEAN MCCLOY, M.D., MPH, MA, MEDICAL DIRECTOR, INTEGRATIVE HEALTH CENTER OF MAINE, CUMBERLAND FORESIDE, MAINE

Dr. MCCLOY. Thank you, Senator Collins, as well as to the esteemed members of this panel, and especially to Paula Jackson Jones for setting the temperature controls and getting us all ready for winter.

I am honored to speak about my experiences and my frustrations as a physician treating patients with tick-borne disease. No other illness has been as intellectually challenging to properly diagnosis and manage as Lyme. The more I learn about this disease, the more questions I have, and the more I realize we have just scratched the surface of how complex the answers are. Hopefully your work on the TICK Act will move the research forward and provide more hope and more help to Mainers and to the worldwide public health.

As a young resident at Maine Medical Center, I felt I was well trained in the classic signs and symptoms of Lyme Disease. We were taught to look for the bull's-eye rash, the flu symptoms outside of flu season, the joint pain. Like my colleagues, I treated these acute cases with a short course of antibiotics. However, I began to see more and more patients who did not fit the typical scenario. They never remembered a tick bite; they never had a rash. Their blood testing was negative for tick-borne illness, but they grew sicker and sicker despite seeing multiple specialists. I had to become a detective doctor to figure out how to help these people. I needed new tools for my tool box.

I began attending conferences run by the International Lyme and Associated Diseases Society, or ILADS, and learned that there was more to the story than the basic model I was taught in medical school. I learned that there were differing opinions and conflicting guidelines between the Infectious Diseases Society of America, or IDSA, and ILADS. In short, IDSA states that Lyme disease is easily diagnosed with standard two-step blood testing and easily treated with a short course of antibiotics. If patients' symptoms persist, it is because of the damage already done and not because of a lingering infection. ILADS' view is just the opposite: the standard testing may not be accurate because of how Lyme can fool the immune system, and a short course of antibiotics may not be enough to eradicate all organisms in a person's body. ILADS feels that chronically ill individuals need a more comprehensive and long-term therapeutic regimen to treat their real disease, and not just be dismissed as suffering from "the aches and pains of daily living."

Here we had two groups of very smart doctors, both wanting to help their patients, at loggerheads over how to diagnose and treat Lyme disease. This conflict left me and my patients in the middle searching for solutions. Now, I have got a Master's in Public Health and a Master's in Medical Sciences, so I love research. I dove into the literature from the standpoint of an open-minded skeptic. I read both sets of guidelines. I read the peer-reviewed journal articles supporting both sets of guidelines. I looked into who the authors were and who was paying for their research. In the end, I tried both sets of guidelines on my real-life patients to observe which approach works best.

I found there was room for both the IDSA and ILADS solutions depending on the situation. The IDSA approach works well for acute, classic Lyme disease. If a person has a strong, healthy, robust immune system at baseline, then the testing should begin to turn positive after 2 to 3 weeks of infection. Fortunately, this infection is usually very easy to treat with a short course of antibiotics if you catch it early.

Unfortunately, if you do not catch it early, this smart little spirochete begins to go through its own life cycle. It changes its shape and hides from the immune system, causing inaccurate, false negative blood testing. It creates a physical barrier called a "biofilm" that protects it from antimicrobials and from your own white blood cells. We are discovering what are called "persister cells" that are resistant to antibiotic therapy. They can remain dormant in a human body for months or years before they wake up again.

In the unfortunate individuals who become chronically ill, multiple systems are affected. There is a complex interplay of genetic factors, inflammation and immune dysregulation, hormonal imbalance, neuroendocrine disruption and neuroinflammation leading to cognitive deficits and psychological illness, gastrointestinal dysfunction causing nutritional insufficiencies, which create metabolic imbalance and poor mitochondrial function, leading to the chronic fatigue that many describe, so lots of big words there. As I learned, a few weeks of antibiotics are not enough to heal these complex cases.

The ILADS approach works better for these types of patients. It is an individualized, head-to-toe, integrative method of figuring out what is broken, what are the root causes of the illness, and how to help that person heal from the inside out. It is certainly not a perfect approach. Sometimes it requires long-term antibiotics that have their own risk of side effects. It is complicated and it takes a lot of the practitioner's time to do the detective work. It also takes a lot of the patient's time and energy and health care dollars to walk that road to recovery. These people need a lot of support to get them through the bad days. Eventually, they celebrate more and more good days and move forward to remission.

To summarize, I have learned that there is no perfect set of guidelines, no one-size-fits-all algorithm that works for every case in the real world. The testing is imperfect. The medications do not always work. Some people get better right away, and some people develop problems that linger for years. The classic presentation of Lyme disease that physicians learn about in medical textbooks does not always apply because the little bug forgot to read the textbook.

We need more answers, Senator Collins. How can we prevent the illness in the first place? How can we improve the accuracy of the testing? How can we tell which treatments work best, and how do we know when to discontinue a regimen? Your excellent work with the TICK Act will hopefully help provide more answers to the doctors and patients out there dealing with tick-borne disease.

Thank you very much and be well.

The CHAIRMAN. Thank you very much, Doctor.

Ms. Jackson Jones.

STATEMENT OF PAULA JACKSON JONES, PRESIDENT AND CO-FOUNDER, MIDCOAST LYME DISEASE SUPPORT AND EDUCATION, NOBLEBORO, MAINE

Ms. JACKSON JONES. Chairman Collins, thank you for holding this hearing and for inviting me to testify today. My name is Paula Jackson Jones, and I am here to share with you my personal story and my life's work. This has been a 10-year crusade for me, with the first 5 years fighting for my life and the latter fighting on behalf of others.

I was bitten by a tick in October 2009 while outside doing fall cleanup with my husband. At the end of the day, I discovered a tick embedded in my side. We removed it, flushed it, and did not gave it another thought, not even when I became symptomatic 10 days later. For the next 2 years, I was misdiagnosed by 23 doctors and specialists with everything from panic attacks to respiratory infections, chronic fatigue to fibromyalgia. When my neurological symptoms intensified, a scan revealed lesions on my brain, and I was diagnosed with MS. When my symptoms became even more severe and I was not responding to treatment, I was reevaluated, and my diagnosis was changed to Parkinson's. I was 36 years old.

When I began to have trouble swallowing and the use of my arms and legs was a daily challenge, my medical providers wanted me tested for ALS. I knew that was a death sentence for me, and it was at this point I knew that I needed to fight and advocate for myself.

Thanks to a family member who kept pressing me to be checked for Lyme disease, even though I had four negative tests, I demanded to see a provider who knew about Lyme. My primary doctor refused to give me a referral because that was not what they thought I had. However, the intern gave me a scrap of paper with the name of someone he knew who saw Lyme patients, and in April 2011, after clinical examination, additional blood work, and tests, I was officially diagnosed with late-stage neurological Lyme complicated by Babesia, Bartonella, Rocky Mountain spotted fever, and ehrlichiosis. I was CDC-positive for all these tick-borne diseases. That Maine doctor, the 24th medical provider that I met with, not only saved my life but gave my life back to me.

When a cancer doctor thinks outside the box and heals their patient, they are deemed a hero. When a Lyme provider does it, they are brought up under medical scrutiny and disciplined beyond belief.

My treatment was not conventional or mainstream, but it was effective. It was tailored to my infections and to how I was responding every step of the way. Thankfully, my medical provider had a vast amount of resources to turn to when treatment options failed, which they did, and I am so grateful for my health today.

In April 2014, after going into remission, I wanted to make a difference by raising awareness about the risk of tick-borne disease, educating people on how to protect themselves, but more importantly, I wanted to make their search for resources easier, accessible, and affordable, and so I co-founded Midcoast Lyme Disease Support and Education to connect patients and their families with the services that they need to journey back toward health and wellness. We are a nonprofit 501(c)(3) organization that travels statewide, raising awareness, fostering education, advocating for change, and providing support to those in Maine afflicted by tick-borne disease by linking them with medical providers, educational programs, and financial assistance. We are also the Maine partner of the national Lyme Disease Association, members of Maine's CDC Vector-borne Work Group, and active in Maine's Lyme legislation movement.

In 2018, I served as the co-chair to the Federal Health and Human Services Tick-borne Disease Working Group's Access to

Care Services and Patient Support Subcommittee. Our task was to identify gaps and barriers that patients faced in accessing proper diagnosis and treatment. That information went into a report and was presented to Congress. I was very honored to have been selected for that role.

Tick-borne disease is not a cookie-cutter disease, which explains why the cookie-cutter approach has failed time and time again. Today each of us on this panel has highlighted the increasing incidence of tick-borne disease infections and even viruses which could cause serious illness and death. Excuse me. The actual numbers are likely much higher since experts agree that the public health burden of tick-borne disease is considerably underreported. That is why it is so imperative that we adopt an all-hands-on-deck public health approach. We need to build a robust understanding of pathogenesis, design improved diagnostics, and develop preventative and effective vaccines. We need to fix faulty tests and increase physician education. Enacting the TICK Act that Senator Collins introduced will provide a lifeline not only to patients but to medical providers. With funding available for research and education, we can get medical providers on the same page, not only with improved diagnostic tools but better, more effective treatment options for their patients. With the TICK Act, we can stem the growing threat of tick-borne disease.

Thank you again for this opportunity, and I look forward to your questions.

The CHAIRMAN. Thank you so much for your moving testimony and sharing your personal odyssey with us and all the good work you have done for others as well.

Ms. JACKSON JONES. Thank you.

Mr. Philbrook.

STATEMENT OF CHRISTOPHER PHILBROOK, INDIVIDUAL AFFECTED BY LYME DISEASE, CUMBERLAND, MAINE

Mr. PHILBROOK. Thank you, Senator. It is a small thing, but I did not realize how important smiling was to my mental health until I could not do it anymore.

On a Saturday afternoon in 2007, I took a trip to Hogback Mountain in Virginia. Shortly after that trip, I woke up incapacitated. I could barely move a muscle. I thought it might be the flu, so I stayed in bed and did not think much of it. I have always been healthy and quick to recover, so when my condition did not improve in a few days, I flew back to the great State of Maine to see my doctor.

One problem with Lyme disease is that the symptoms mimic so many other things, as I would soon discover and as Paula just mentioned in her testimony.

When I got home, my seventh cranial nerve, which runs down the left side of my face and you can still see, went into a State of trauma. In addition to flu-like symptoms, I now also had Bell's palsy. I also could not eat or sleep for days and was in a State of pain so debilitating that I went to the emergency room and received a CAT scan. The scan showed nothing abnormal, so the doctor suggested I see a neurologist.

I also scheduled a dentist appointment to see if something was wrong with my teeth because they hurt badly. The dentist took one look at me and said, “Bell’s palsy can be the result of Lyme disease. Do you have a tick bite or a bull’s-eye rash?”

I did not. I mentioned this to my neurologist, and he tested me for Lyme. The test came back negative—a false negative, which is something Dr. McCloy just said in his testimony. Shortly after that, the right side of my face went into a State of paralysis. I now had Bell’s palsy on both sides of my face, and my mouth was almost completely wired shut, so the neurologist recommended an MRI. The MRI showed what looked like a tumor either growing or blocking my cavernous sinus, which is a nerve that runs from the brain to the face. We started talking about surgery and radiation. Now I am starting to worry.

Next, the neurologist recommended a spinal tap. If you have never had a spinal tap, consider yourself very lucky. It is awful.

When the neurologist also ordered a second MRI, this time injecting a blue dye into my body so the tumor would show up in greater detail, he also ordered a chest X-ray because I was having trouble breathing.

The spinal tap showed Lyme in my spinal fluid, and the blue dye showed that the disease had attacked the nerves in my brain, causing extreme inflammation, but the good news? I did not have a tumor.

I did, however, need a PICC line immediately installed. For 4 weeks, the line delivered a strong dose of antibiotics from my bicep to my heart.

I was working on Senator Collins’ staff at the time. She watched my pain and suffering firsthand. I still have daily notes from her checking in on me. One said, “You gave us quite a scare.”

It was scary, and it remains scary today knowing that even in my back yard there are ticks. With its proposed public-private partnerships, including pest control, the TICK Act aims to alleviate this threat—a prospect that would relieve a lot of anxiety for anybody who has gone through this.

I was lucky my dentist spoke up, that I had a spinal tap—not a normal Lyme testing protocol—and that my Lyme disease was treated quickly, within the first month and a half. I am happy to say that after my antibiotic treatment, I was cleared of the disease, although the residual effects remain—mainly sleep disturbances and facial paralysis, which you might not notice in the audience, but I am quite certain that the cameras will pick it up, because I have seen it.

Others are not so lucky. When Lyme is not diagnosed quickly, co-infections can develop, and the disease can become much more difficult to treat. This happens far too often, which is why the TICK Act’s directive for improved diagnostic testing is so important to me.

For my ongoing symptoms, the most effective relief has come from food. After 8 years without improvement and having been told the only solution to improve my facial paralysis was plastic surgery, I started on a ketogenic diet and intermittent fasting—something author Tim Ferriss said was the only thing that knocked out his Lyme disease. Within 7 days, I felt movement in my face that I had not felt in years. Because ketosis—nutritional ketosis, which I was trying to achieve—is unrealistic for me to maintain over the long term, I have fallen back on Tom Brady's eating and training regimen, the TB12 method. I figure if it is good enough for him, it is definitely good enough for me.

While this approach may not work for everyone, it did work for me. The problem is my story does not scale. I heard this approach by chance on a podcast. Conversely, the TICK Act would create a data base where the treatment approaches and outcomes could be shared immediately in the context where it matters most: in the doctor's office.

Thank you, Senator Collins, for this opportunity and for your work on this public health threat. I hope the TICK Act, when enacted, gives people currently suffering with Lyme disease validation and hope that they can and will get better.

Thank you.

The CHAIRMAN. Thank you so much, Chris. I so remember when you got the results that suggested you had the tumor and how worried we were, and then when it turned out that it was not a tumor, we were still so worried because of the symptoms and pain you were experiencing, and I want to thank you for sharing your story with us today as well.

Dr. Dill, I would like to start my questioning with you. You told us how UMaine Cooperative Extension accepts tick submissions to identify the different types of ticks and whether or not they are carrying a pathogen. Could you give us some idea, since April 1st when you first got the lab located here and up and running, and the end of July about how many ticks have you received from Mainers?

Dr. DILL. In that short period of time, we received, as of yesterday, 1,837 ticks.

The CHAIRMAN. So I think that is remarkable because a lot of people are unaware that you will do this service. In fact, I am a little worried that this hearing is going to overwhelm your resources, so that is further reason for me to get the TICK Act passed as soon as I can.

Dr. DILL. Exactly.

The CHAIRMAN. Of those ticks tested so far by the University of Maine, can you give us an idea of approximately what percentage of them carried some sort of disease and Lyme disease specifically?

Dr. DILL. Of the ones tested, which was about 1,150 ticks that we have actually tested, 42.5 percent of them have carried some type of pathogen; 37 percent of them actually carried Lyme disease, and of course, that is statewide, and just to carry that further, anaplasmosis was 8 percent and babesiosis was 6 percent.

The CHAIRMAN. So that is a substantial number. Is the university trying to figure out the geographic distribution and whether there are hot spots in the State? You know, I remember when Lyme disease did not even exist in Maine, and then each year we have seen more and more cases, and also they seem to be expanding northward, but still there seems to be a difference in the geographic distribution.

Dr. DILL. Definitely a difference in the geographic distribution. Especially as you go from south to north, it gets fewer and fewer. Coastal areas and southern Maine is really right now our hot spots, but what we are doing is with the surveillance that we are doing with the ticks being tested, we actually have some ongoing work, and we are working with Maine Medical Center, who is doing surveys also in, I think, all 16 counties, and we are testing the ticks for them. So it is a great collaborative effort we have in the State of Maine. So we are looking at this type of thing as we move forward, trying to get some type of distribution.

The CHAIRMAN. Thank you.

Dr. Petersen, in 1947—and, no, I was not alive then.

In 1947, we launched the National Malaria Eradication Project, and this Federal program, with State and local participation, succeeded in eradicating malaria from the United States in a very short period of time. I think it was by 1951, and the antimalarial campaign involved large-scale public health initiatives.

Our approach to tick disease, tick-borne diseases and Lyme disease, is very fragmented today, and it really relies on the individual, people like Paula and like Chris, with their physicians, to try to figure out what in the world is going on. So with the TICK Act's national strategy, we are seeking to ultimately halt the progression of Lyme disease. That is an ambitious goal.

Since you have so much experience with other epidemics and at the CDC, could you explain to us the difference that a larger-scale public health approach at the Federal, State, and local levels could—what promise that holds for Lyme disease control and prevention?

Dr. PETERSEN. Thank you for the question. I think one thing that is very important to know is if we do not do anything large, like on the scale of what you were talking about with malaria, this is just going to continue to get worse and worse, and so there is really an urgent need to try and figure out how to better control these tick-borne diseases in particular.

One of the advantages that they had with malaria was that there was DDT and other things that we may not want to use right now that could effectively control the mosquito vectors. Unfortunately, for Lyme disease and other tick-borne diseases, we do not have really good strategies, like a real unified strategy that will work to control these ticks.

We really need to find better ways of controlling ticks, and in the meantime, we need to better do better surveillance for the ticks to see where they are, as Dr. Dill has mentioned, as well as trying to figure out how to better diagnose patients, as several of the panel members have mentioned, so there is no simple, easy answer, but it is going to take a concerted effort of State, local, Federal, private institutions all working together to try and find solutions for this growing problem.

The CHAIRMAN. I was struck in your testimony when you pointed out that there is no vaccine that is available for Lyme disease, and I was thinking about that because my husband and I got a dog a year and a half ago, and we had her vaccinated for Lyme disease. So I know this is not exactly under CDC's purview, but I am sure you are a partner with the NIH and others, but what are the barriers to developing a vaccine? And is that an approach that we should be pursuing?

Dr. PETERSEN. Yes, so we are very in favor of someone producing a very safe and effective vaccine for Lyme disease. I think ultimately this is going to be one of the key answers in trying to control Lyme disease. The key is it has got to be safe and it has got to be effective, and there is just a much higher bar for proving safety and efficacy in humans than there are, let us say, for your dog, with obvious reason, and so there is a company called "Valneva" that is in Stage II clinical trials with a Lyme disease vaccine both in the U.S. and in Europe, but it is still going to take several years to be able to bring this vaccine to market.

The other thing to keep in mind is a vaccine is not the magic bullet for this. Certainly, if a safe and effective vaccine for Lyme disease is produced, that is great. We have got a huge increase in Lyme disease, but we have to remember that the same tick that spread Lyme disease spreads a lot of other diseases, like anaplasmosis, Powassan, and so it is going to take both an effort of vaccine development as well as better ways of controlling ticks to ultimately find the right solutions for this.

The CHAIRMAN. I am encouraged to know that there are some Stage II clinical trials going on. That is encouraging.

Ms. Jackson Jones, treatment for Lyme disease can be very expensive, and you talked about—I think you said that you went to more than 20 doctors to try to get an accurate diagnosis. We have heard from Chris about his odyssey and having MRIs and CAT scans and even a spinal tap and going to his dentist, who, fortunately, made the link. So talk to me about how expensive it can be to get an accurate diagnosis and treatment.

Ms. JACKSON JONES. Well, my personal journey, we are in the neighborhood of $250,000, and I stopped counting when I went into remission. There are still support measures and support finances that you go through. There is damage control. You know, my pancreas, my liver, my kidneys were collateral damage in the treatment journey, both from misdiagnosis, you know, all the different antibiotics that I took before finally getting the proper diagnosis. So I could almost double that number easily, because I am still taking support measures today to support my adrenals because I am very active, so just to keep me healthy, but also to piggyback off what Chris said, you know, diet plays a huge part in it, and we all know if you eat healthy, it is not cheap either, so, you know, just trying to stay healthy, stay with a healthy diet, exercise, reduce the stress, there are costs associated with all of that, and it is not something that is affordable by everybody.

The CHAIRMAN. That is an extraordinary burden on top of the disease.

Dr. McCloy, you talked about the disagreements among medical professionals on what should be done, and we also have an issue where the testing produces a lot of false negatives because it takes a while, I assume, for the antibodies to show up, and there is this two-stage blood test. So not to personalize this, but when I had a tick recently, my doctor did not do the test thing. She immediately gave me two doses of doxycycline.

Wouldn't it make more sense to start treating even if you have not gotten the test results back yet to prevent long-term damage or to stop the disease in its tracks?

Dr. MCCLOY. That is my own personal approach in my practice as well, but not all physicians would agree with that. I have been surprised at the sort of war going on out there in the medical world, in the medical community, and personal attacks between physicians over this whole Lyme disease question. So I think every physician has differing opinions and a different scale of training and education around what they are doing in their own practices, and the guidelines really do vary on what to do with that kind of circumstance. If you have got a person with a tick bite, do you treat them right away? Do you wait until the results come back? Do you wait until symptoms develop? If it is a pediatric patient, what do you do with a very small child?

We have to remember the antibiotics themselves have a lot of side effects and potential damage, too, so it is always a risk/benefit discussion with each individual patient.

For me, because I have seen the damage done to chronically ill individuals, I am a little more aggressive in my own strategy, so I definitely would treat early and have the tick sent off for testing and even begin treatment while the tick itself is waiting to come back.

The CHAIRMAN. Dr. Petersen, are there efforts underway to try to improve the testing process so that you get quicker results or there are not so many false negatives?

Dr. PETERSEN. Absolutely, and I think with the treatment, I think as the Nation's prevention agency, we would say the best treatment for all these diseases is to prevent them in the first place. However, you know, you have had our other panelists as well as people in the audience that have made it quite clear that the burden of the disease is quite high, and I think the first step in treatment is to do the proper diagnosis and get better diagnostic tests, and these are sorely needed, as was mentioned by several of the other panel members, and so we are engaged in a number of efforts to try and improve diagnosis. It is a huge effort on our part. We are working with other Federal agencies such as the NIH, private companies, and academic institutions to try and better improve the diagnosis, not only for Lyme disease but all of the vector-borne diseases.

The CHAIRMAN. Thank you.

Mr. Philbrook—I know you like me to call you "Mr. Philbrook." You know, one of the aspects of your terrible journey with this disease that so impressed me is you just kept trying to figure out what was wrong, and Paula did also. You did not give up, and you have also maintained this unbelievably positive attitude, which is really inspiring.

Looking back at your own battle against Lyme disease, what advice would you give to an individual who is newly diagnosed with Lyme or another tick-borne illness?

Mr. PHILBROOK. Sure, and Paula mentioned this in her testimony. I think you need to be your own advocate right from the start. Do not be afraid to bring your physician research that you have seen, things that have worked for other people, because there is often an individualized approach to treating Lyme disease.

I also would just say to take it very seriously and give yourself some time to get better. It is attacking your nervous system, so you really need to take that time in your life to get better.

The CHAIRMAN. Tell me what you do—I know you have a child now, and if you have all been—your family has been outside. Do you check yourself when you come back in? Or what do you do on the prevention side?

Mr. PHILBROOK. Sure. We do a few basic things; like tucking your pants into your socks is an easy way to help prevent ticks from entering your body.

The most important thing we have done, honestly, is a very simple step, which is take a shower as soon as we get back inside, whether it is hiking, gardening, just being outside at all, because a lot of times, at least in our experience, the ticks have not attached yet and they wash right off and down the drain, and that has been a huge preventative step we have taken.

Obviously, watching much more carefully my daughter than probably most people, but, you know, you check behind the ears, you check in the hair. Vivien Leigh, who is in the audience, did a great service to Mainers and kind of went through a lot of different ways people prevent Lyme disease and different treatment options as well.

The CHAIRMAN. Thank you.

Yes, Dr. McCloy?

Dr. MCCLOY. One thing I try to educate my patients about is that daily tick check, really 365 days a year, and making it part of your daily personal hygiene. So you brush your teeth at night, you do a tick check, and what I tell my patients is you are trying to find a poppy seed on your body, that is how big some of these ticks are. So find the poppy seed, check your partner, make it fun—you know, check your kids. So that is part of your daily routine.

The CHAIRMAN. Thank you. That is good advice.

Ms. Jackson Jones, you talked about the work that you have done. Could you tell us a little bit—I know you put on an annual conference, and explain a little bit about that conference and what its purpose is and what your goals are with your organization on the Midcoast.

Ms. JACKSON JONES. It is important to us to get resources to people and to introduce them to what all their options are. So every year in the spring we hold an annual Midcoast Lyme Disease Support and Education conference, and we have it slated for April 11th of next year. We had to move it from a small community center to the Augusta Civic Center because we grew so fast.

We bring in doctors, researchers, labs, medical facilities, all types of businesses that come in, anybody that has a connection to Lyme and tick-borne disease. We have Dr. Dill come in, and he, you know, shares what the labs are doing. It is important to us to bring what is going on around the world to the people of Maine, and what better way to do it than to bring the speakers in themselves, to bring the researchers in to talk about the latest diagnostics. The labs will share what their latest tests are available. This is good not only for the patients but for the doctors to know what resources are available. So the speakers get a chance to present what is new in the form of diagnostic testing, treatment, support, and then we have anywhere from 100 to 125 exhibitors there where people can go up and actually network for free and get firsthand, one-on-one experience with them, talk to the many different providers. If you are in the market for a new Lyme provider and you just do not know what Dr. McCloy offers or what somebody else offers, talk to them. They have all their information there. You can talk to them, set something up. You can talk to the different labs, find out what testing is going on. You can talk to the different treatment companies that are there and ask, you know, "What is new? What are you doing to combat Babesia symptoms?"—then talk to other people that are there encouraging exercise and food and stress reduction.

More importantly, we do it all for free. It does not cost anything to walk through those doors. We get Federal grants. We get State grants. We get a lot of donations. We do charge our exhibitors to have a booth space there, and we make sure that it is always free. If somebody has got $20 left to their name, I mean, to put that in their tank for gas, just to show up to get connected to resources, we want to make sure that that happens.

The CHAIRMAN. That makes a great deal of sense, and I know your conference is extremely valuable in educating people.

Dr. McCloy, it sounds to me, when we listen to Paula's and Chris' experience, that there is not a one-size-fits-all approach to tick-borne illnesses. Has that been your experience, that you have to tailor it to the individual?

Dr. MCCLOY. Absolutely. Yes, the disease affects different people in different ways, so it depends on which systems of their body it is affecting. That is why it is called "the great mimicker" these days. It mimics a lot of other illnesses out there.

The diagnosis is quite challenging, too. A lot of physicians go with what is called a "clinical diagnosis," meaning that if this person presents with a good story, if they have been in a Lyme-endemic area, they are outdoors, they get these illnesses, these symptoms present, that you need to rule out the other diseases that can cause those same symptoms, but if they have got 36 out of 38 symptoms of Lyme disease, they probably have Lyme disease, but you still have to do your due diligence as a physician and rule out the lupus and the autoimmune conditions and the fibromyalgia and all these other things that could present similarly, so it takes a lot of time. It is quite challenging to do that as a physician. I think that is one of the limitations in our kind of conventional medical care system, where the physician might have 7 to 11 minutes with a patient per visit. It is hard to figure it out in that amount of time given.

The CHAIRMAN. I would think that it would be.

Dr. Dill, if the TICK Act were to become law, which I am determined that it will, how would it be helpful to you and the important work that you are doing at the university?

Dr. DILL. I think one of the things that is happening, of course, there are lots of threats coming in with the ticks. There are new species knocking on our door. There are new diseases associated with them, and even if you just take Lyme disease, there are several different strains of the disease, and some are more virulent than others.

Some of the things that would help with us is that I think that even though the stage has been really good to us, as you can see looking at this facility, and in other ways funding still has not kept up with anywhere what it needs to be with education and management strategies, surveillance, and as we were talking as we walked through here, we could probably hire 25 people just in the tick lab in the State of Maine and not make a dent in all the research and that type of thing that needs to be done, so it would just be an awesome, you know, boost to the research side of the community here at the university, the Maine Medical Center, the CDC. We all work together, and it would be a great boost to all of us.

The CHAIRMAN. Thank you.

Dr. Petersen, the TICK Act would also reauthorize the CDC's Regional Centers of Excellence for Vector-borne Diseases at $10 million per year for each of the next 5 years, and I am worried because the funding for those centers expires next year at the end of the fiscal year, so I want to make sure that does not happen, and that is part of the TICK Act as well.

Could you share with us how these centers have advanced our understanding of tick-borne diseases and why we should continue to fund them?

Dr. PETERSEN. Yes, thank you for the question. The Centers of Excellence is a new concept that we had following the Zika virus epidemic, and the idea was to try and merge academic institutions with State and local health departments and develop communities of practice in their areas, among multiple States, as well as trying to train the next generation of medical entomologists, like Dr. Dill, which he can testify to the fact that there are very few medical entomologists right now. You mentioned malaria. The CDC, half the staff of CDC used to be in the mid–1940's in entomology. Now when the Zika virus epidemic happened, out of our staff of 12,000 or so, we had 12 medical entomologists, so we need to rebuild this whole field.

Some of the examples of the work that the Centers of Excellence have done, one was just to do the tick surveillance, for example. Not only would we want to do more in Maine, but we would want to do more around the whole country, develop a true national tick surveillance network in all the States.

Another thing that we are doing here with the Northeast Center of Excellence, for example, is working on this new Asian longhorned tick, trying to figure out what diseases it spreads, where it is, you know, how it infests animals, how it infests people, and so that has been a very important part.

We are also working with the various Centers of Excellence on developing better diagnostic tests. As you heard, it was a huge problem with many of the diseases we deal with, so at CDC we have a certain capacity, you know, we have a certain staff, but by incorporating all these Centers of Excellence around the country, it enabled all of our efforts to expand with our university partners, which has been very, very critical and actually has worked well beyond my wildest dreams.

The CHAIRMAN. That is great to hear. Thank you.

Would any of our witnesses like to add anything before we close the hearing? Is there any issue that you want to make sure is on the record that I did not touch on through questions or testimony? Paula.

Ms. JACKSON JONES. I think the one thing that most patients can agree on is if we miss the window, the early window of opportunity where our infection moves from acute to chronic, that is where things get really muddy. That is where the diagnostic tools start to fail us. That is where the treatment options—there are no instructions. Everything that has ever been written, including in the ICD–10 code for insurance, that has all been written for acute, so one of the biggest hurdles is, you know, once you outgrow that window and you move into Stage II, Stage III, Stage IV, there are no instructions for doctors at that point. They are trying to make you fit into that acute box, and that acute box says you only get 2 weeks of treatment, and they are trying to be creative and think outside the box and think, “What can we call this so that the insurances will cover it?” If the doctors cannot even give it a name, how can they treat it?

I would like to see—and that is something that I would like to see at a national level. I think we need to give it a name. We need to agree on what we are going to call it. We need to give it an insurance code, and then we need to agree on how we are going to approach it for treatment, but as Senator Dill—excuse me, Dr. Dill——and Dr. Petersen both alluded, I mean, even like with the vaccine, you know, with a treatment plan, it is only going to go after one thing. If you have two or three co-infections, things start to get a little muddy, so I think having treatment options is the answer and stop making it so cookie-cutter. If we have to give it a cookie-cutter name, then we give it an ICD–10 code and we let the doctors go from there and treat their patients.

The CHAIRMAN. Very good points. Thank you.

Dr. Dill?

Dr. DILL. I would just add that when we are talking about the statistics on the amount of Lyme disease, et cetera, the one thing I did not mention and it was just brought up was about 8 percent of the ticks tested have had co-infections, so it is prevalent. There is more than one disease associated with an individual tick, and you may be looking at one disease, and you actually have two or three, so it is crucial all the way around.

The CHAIRMAN. Thank you.

Dr. Petersen?

Dr. PETERSEN. Yes, I think one thing that is important is that we absolutely need a very large-scale project or a big effort to try and figure out how to better control these ticks, but in the meantime, I think is very important that people protect themselves against tick bites by wearing permethrin-treated clothing, by putting on insect repellent, by tick-proofing their yard, because you have heard about some of the devastating effects of some of these tick-borne diseases, and the best way to prevent that is to prevent it, and so it is very important that State and local health departments work with academic institutions, private organizations, you know, patient groups to try and spread the world about how people can actually prevent tick bites.

I met with the Maine CDC yesterday. They are doing an outstanding job on trying to educate the public on how to do it. It is not so easy. These ticks are very small, but people need to remain vigilant, and we keep—we need to push that effort to make people aware of these kinds of problems and how to prevent them.

The CHAIRMAN. Thank you.

Dr. McCloy?

Dr. MCCLOY. We touched briefly on the financial impact of this disease on patients and individuals and also touched briefly on the insurance companies' coverage of the treatments. As a physician, I often see my patients running up against that barrier where their insurance companies do not approve more than, say, 4 weeks or so of antibiotics, and we have to help them navigate appeals processes, et cetera.

Some States have passed legislation mandating the insurance companies to cover for a longer-term treatment, but it has been a little piecemeal, so, again, as part of a national effort, it would be nice to see some sort of legislative effort to mandate insurance companies to cover not only longer-term antibiotics but also the other integrative therapies that Paula has discussed. You know, all these various impacts on her body, you cannot just throw 4 weeks of antibiotics at that kind of a situation. You have to treat it holistically and comprehensively, and that financial limitation is tough for patients, so having insurance coverage mandated would be a huge help for these patients.

The CHAIRMAN. Well, her $250,000 in medical bills is just such a burden on top of the disease. It is just incredible, and I think the point is well taken that insurers have not figured out that there are chronic cases and with diverse symptoms and that it does not fit neatly into one insurance code for reimbursement, so those are both good points.

Chris, we are going to allow you to finish up the testimony today.

Mr. PHILBROOK. Thank you. I hope this act just generates—and it is generating awareness for people to be thinking about this. Dr. Petersen mentioned prevention, and that is a key piece, but everybody in this room can be an advocate for themselves, can ask their friends that may be going through something like this, if they have asked their doctor about Lyme disease and just consider it as a possibility, and then just keep asking the question.

I am excited that this act is on the table because I think it is generating a significant amount of awareness that this disease deserves, so thank you.

The CHAIRMAN. Thank you.

I want to thank all of our witnesses today for sharing your stories, your expertise, and your insights. Your testimony today shines a bright lime-green spotlight on the growing crisis of tick-borne illnesses and is a spur to action.

We live in a State where we love being outside. It is part of our heritage in Maine, to be outside, to take that walk in the woods, to go hunting, to do gardening, and we want to be able to continue to enjoy what makes Maine so special, and the great outdoors and the recreational opportunities it offers clearly are part of that, so that is why I have become really determined to look for alternative, broader approaches to attacking this epidemic.

Again, I will start where we began, and that is, on a per capita basis, Maine has the highest incidence of Lyme disease in the Nation, so we are particularly affected, and of those Mainers and of people nationwide who get tick-borne illnesses, those aged 65 and older are at particular risk. Since Maine is the oldest State in the Nation by median age, that adds to our vulnerability.

Prevention remains so important, as we have just heard from Chris and other witnesses, being an advocate for yourself, but I also believe that we need to turn the corner and adopt a public health approach and make this a national priority just as we did with the eradication of malaria so many years ago, and if we can join forces and collect data and share information, disseminate best practices, raise public awareness, educate health care professionals, work with the researchers in the labs like here at the university, which does such a great job, and work with our partners at the Federal level and with those Regional Centers of Excellence, I believe we can make a real difference.

I am grateful for all of our panelists for adding to my knowledge as I continue to advocate in Washington for passage of the TICK Act. I think it truly would help us turn the corner and adopt a whole new public health approach to combating these tick-borne illnesses, so I want to thank all of you for being here today and helping us change the trajectory of tick-borne diseases.

I also want to thank my staff, Sara in particular for her very hard work on this issue. She is a public health expert and has helped in developing this new approach that we are going to be pushing hard.

My thanks to the University of Maine, the Cooperative Extension Service, and the tick lab in particular for graciously hosting this event. I am very proud of the work that is being done here at the university and hope that with the additional funding that would be available through the TICK Act that we can expand that work and give you even more resources.

I have a feeling, after this hearing and with the dissemination of these kits, that that number of ticks that are sent into the lab may well increase, and that is a good thing, but I know you need the staff to handle it as well.

The hearing record will remain open until Friday, September 13th, in case there are additional questions that we may be sending your way, but again, my great appreciation to all of you for being here today. You added immensely to our knowledge.

My thanks to all of you who have participated in so many ways, so many of you who are sitting in the audience have shared your personal stories with us and your scientific expertise in helping us draft the TICK Act, so I am very grateful for that.

This hearing is adjourned. It is official. Thank you.

[Whereupon, at 11:26 a.m., the Committee was adjourned.]

APPENDIX

Prepared Witness Statements

Written Testimony
Senate Special Committee on Aging
Field Hearing

September 5th, 2019

Statement of

Lyle Petersen, MD, MPH

Director, Division of Vector-Borne Diseases

Centers for Disease Control and Prevention

Department of Health and Human Services

For Release on Delivery

Expected at 10:00 AM

On Thursday, September 5, 2019

Introduction

Good morning Chairwoman Collins and members of the Special Committee on Aging. I am Dr. Lyle Petersen, Director of the Division of Vector-Borne Diseases in the National Center for Emerging and Zoonotic Infectious Diseases at the Centers for Disease Control and Prevention (CDC). Thank you for the opportunity to testify before you today on CDC's ongoing efforts to protect the U.S. from the growing threat of vector-borne diseases, and tickborne diseases in particular. CDC appreciates your continued commitment and support of our work in this area.

As the director for the Division for Vector-Borne Diseases for CDC, I lead our agency's efforts to research, prevent, and control viruses and bacteria spread by mosquitoes, ticks, and fleas. These vectors of disease transmit over 100 pathogens known to infect people, including those that cause mosquito-borne West Nile and Zika, tickborne Lyme disease and Rocky Mountain spotted fever (RMSF), and flea-borne plague. Together, vector-borne diseases account for 17 percent of the estimated global burden of all infectious diseases.

CDC recently examined trends in vector-borne diseases and what we found illustrates why these diseases are a major public health threat. We found that vector-borne disease cases reported by states to CDC tripled from 2004 to 2016, marked by numerous high-profile mosquito-borne outbreaks with a steady and concerning increase in tickborne diseases. Reports of tickborne diseases alone more than doubled during that same time period. We know that this is a small fraction of total vector-borne disease cases, as only about one-tenth of Lyme disease and one-twentieth of West Nile virus cases are reported each year by states. Despite this under-reporting, in 2017 state and local health departments reported a record number of tickborne disease cases to CDC for ***all*** nationally notifiable tickborne diseases, including Lyme disease, anaplasmosis and ehrlichiosis, spotted fever rickettsiosis (including Rocky Mountain spotted fever), babesiosis, tularemia, and Powassan virus disease.

In 2017, on a population basis, Maine had the ***highest incidence of Lyme disease in the nation***, with more than 1,800 cases of confirmed and probable cases of Lyme disease in just one year. On a population basis, Maine also had the ***second highest incidence of anaplasmosis***, second only to Vermont. Reported vector-borne disease cases have continued to rise steadily over time in Maine, with more than 2,600 cases of vector-borne disease reported in 2017, which is the last year for which we have complete data. In 2017, more than 98 percent of reported cases from Maine were for tickborne disease, including Lyme disease. These rates may be driven by geographic differences in risk, differences in local awareness, and state-to-state differences in practices for collecting and reporting such data.

Prevention of Vector-Borne Diseases

As you may already know, Lyme disease is caused by an infection from bacteria that is spread through tick bites. Using administrative claims data, CDC estimates that there are more than 300,000 cases of Lyme disease each year in the U.S. It is the most commonly occurring vector-borne disease and the sixth most commonly reported nationally notifiable infectious disease. CDC has a long-standing commitment to preventing Lyme disease and is on the forefront of prevention and control research. CDC scientists have been working together to understand the complicated interactions among ticks, animals, and people to find easy, effective, and affordable means for people to fight this disease. We are also strengthening our understanding of disease risk and burden through data collection and analysis; improving early and accurate diagnosis and treatment, and building collaborations with key prevention partners, including the regional university-based vector-borne disease Centers of Excellence.

We understand that the diagnosis of Lyme disease can be a scary and uncertain time for patients and their families. CDC is working to disseminate the best scientific information available to healthcare professionals and patients and working with state and local partners to ensure that current Lyme disease prevention tools and information are easily accessible, through either CDC or state and local resources. The increase in funding in 2019 for Lyme disease allowed for CDC to expand support for tick surveillance within states at higher risk for tickborne disease and rapidly assess the public health risks and protective factors associated with the U.S. emergence of the Asian longhorned tick.

Trends in Vector-Borne Diseases

Three major factors contribute to increases in reports of vector-borne diseases. First, we know about more vector-borne germs than ever before and our outreach to physicians has increased. In the last 13 years alone, nine new vector-borne pathogens were identified in the U.S., including the first domestic outbreaks of the mosquito-borne chikungunya and Zika viruses and the discovery of seven new tickborne pathogens in the U.S.

Second, travel and trade are moving more pathogens around the world, as well as the mosquitoes and ticks that transmit them. Infected travelers can traverse the world in a single day and introduce vector-borne pathogens to new locations. There are more than 1.3 billion international tourist arrivals worldwide each year globally. Zika virus was an example of the impact that travel can have on the spread of disease. Zika was one of a number of obscure, mosquito-borne viruses that was rarely encountered or studied prior to the 2015-2017 outbreak in the region of the Americas. Due in part to international travel, Zika virus quickly spread throughout the Americas. The U.S. had over 5,000 reported cases in 2016, most of which were in travelers returning from affected areas.

Finally, existing mosquito and tick vectors continue to expand across the U.S. For example, the *Ixodes* ticks that transmit Lyme disease as well as several other tickborne diseases have now been found in more than 1,500 U.S. counties, covering 43 states. This marks a 45 percent increase in the number of counties that have recorded these ticks since 1998.

An example of the problems we are now facing in the U.S. is the introduction and emergence of the Asian longhorned tick. This tick, first discovered in New Jersey in 2017, has been identified now in 11 additional states ranging from Arkansas to New York and Pennsylvania. This marks the first time in more than 50 years that an exotic tick was newly discovered and became established in the U.S. It causes massive infestations and transmits several vector-borne diseases throughout the world, including an Asian virus that is related to Heartland virus, which is found here in the U.S. Heartland virus, which is a rare but serious virus found in the U.S., has caused the hospitalization of almost all U.S. patients to date. Although this tick has not yet been associated with disease in the U.S., the high rate of pathogen transmission associated with this tick internationally makes it clear that the potential for health impact related to this tick in the U.S. is high. To date, this tick has not been found in Maine; however, ongoing state tick surveillance activities funded by CDC should allow for early detection should that change.

Addressing the Challenges

CDC is now working to determine which pathogens can be transmitted by this tick and what pesticides and repellents can be used to control them and prevent bites. While we conduct this research, we are also working with state partners to understand where this tick can be found in the U.S. We are also working with other federal agencies, including the U.S. Department of Agriculture, to closely monitor the situation and keep states informed of the risks to people and animals. The emergence and response to the Asian longhorned tick, an exotic tick, is a recent example of how CDC works with state and federal partners to assess the potential threat of new vectors and pathogens in the U.S. and determine how to protect people from vector-borne disease risks.

In addition, CDC works to protect America from vector-borne disease risks by supporting vector-borne disease prevention and control capacity within U.S. jurisdictions. CDC, in collaboration with the National Association of County and City Health Officials, assessed the vector control capacity of over 1,000 local vector control departments and districts. Results suggest that four out of five vector control organizations are missing at least one core vector control capacity, such as being able to conduct vector surveillance.

A valuable source of vector-borne disease prevention and control resources extend from CDC's five vector-borne disease Centers of Excellence (COEs). Through the Zika supplemental funding from Congress in 2016, CDC was able to establish five university-based regional Centers of Excellence in vector-borne diseases, to work towards enhancing prevention of and response to vector-borne diseases in their regions. These centers coordinate efforts with public health agencies and institutions to conduct operational research within their region, building partnerships across state lines.

With increased interest and support for vector-borne disease prevention and control activities, we have been able to expand support in all 64 jurisdictions eligible for the Epidemiology and Laboratory Capacity Cooperative Agreement, while providing enhanced support to nine states and one U.S. city at high risk for vector-borne disease. Each enhanced vector-borne disease program included increased state entomological expertise, as well as laboratory activities, case and outbreak investigations, and vector surveillance and management. For the first time, we were able to provide support to the U.S. territories and freely associated states in the Pacific. We were also able to support tick surveillance activities, which better equips states with the information that they need to assess tickborne disease risks and develop appropriate prevention programs that can prevent tick bites and reduce illness and death.

CDC has also been an active member of the *HHS Tick-borne Disease Working Group*, formed in 2016 to include a wide range of federal, patient, and partner organizations. This workgroup has focused on increasing coordination and examining research gaps and priorities. The first report of this workgroup was published in December of 2018 and included 28 recommendations for tick-borne diseases, including Lyme disease. CDC has appreciated the robust and deep conversations of this group and looks forward to continued participation and dialogue.

Conclusion

CDC is committed to reversing the upward trends in vector-borne disease by preventing future infections. However, it is clear that reversing these trends will not be easy. A major challenge is to discover better prevention methods for vector-borne diseases. There are no proven methods to sufficiently control the ticks that spread most tickborne diseases, so prevention relies on personal protection to prevent tick bites. There are also no vaccines available for humans for ***any*** of the vector-borne diseases endemic to the U.S. In addition, although guidelines and recommendations exist for West Nile virus, which is the most common mosquito-borne disease in the U.S., the ability of jurisdictions to implement and evaluate the efficacy of these recommendations varies. Further, no proven control methods exist for some important mosquito vectors, such as those that spread Zika. CDC is committed to making strategic investments in promising new vector-borne disease prevention strategies. We will also continue to support states and jurisdictions in their ability to assess risk through vector and disease surveillance, ensure lab capacity for rapid and accurate diagnosis of vector-borne disease, and support vector control capacity. Finally, we are committed to informing and supporting vaccine development as well as vaccine program implementation, as vaccines for vector-borne diseases become available.

Thank you again for the opportunity to appear before you today and for your support of our fight to protect the U.S. and its territories from the ongoing threat of vector-borne diseases. I appreciate your attention to this continuing threat.

TESTIMONY OF DR. JAMES DILL
PEST MANAGEMENT SPECIALIST
UNIVERSITY OF MAINE COOPERATIVE EXTENSION

SEPTEMBER 5, 2019
BEFORE THE
SENATE SPECIAL COMMITTEE ON AGING

Thank you Senator Collins for the opportunity to speak before the Special Committee on Aging in regard to the increasing challenges associated with combatting tick-borne disease here in Maine. As the Pest Management Specialist for University of Maine Cooperative Extension and a State Senator in the Maine Legislature, I have had the unique opportunity to experience these challenges from both the political and scientific perspectives, but today I will speak from my University perspective.

Tick populations have undergone extensive range expansion over the past 50 years, particularly here in the Northeast. Multiple factors, including reforestation, changes in climate, and increased abundance of wildlife hosts such as rodents and white-tailed deer have contributed to this surge. Maine is a heavily forested state with a largely rural population that spans four degrees of latitude and maintains a robust wildlife population. As such, we have witnessed a dramatic increase in the number of ticks, their geographic distribution, and the subsequent incidence of tick-borne disease.

This increase in tick-borne diseases has rapidly become a significant public health issue in Maine and throughout much of the United States. The incidence and distribution of these pathogens continues to increase, often resulting in severe health issues for those affected. In addition to the public health threats associated with tick-borne disease, societal and economic costs can have significant impacts. Of the roughly 13 tick-borne diseases identified in the United States, five have been found in Maine, including Lyme disease, anaplasmosis, babesiosis, Borrelia miyamotoi disease, and Powassan encephalitis. The primary vector of these pathogens, the deer tick or black-legged tick, has greatly increased in both population size and geographic range within the state. Furthermore, Maine faces significant threats related to invasive tick species including the lone star tick and Asian long-horned tick, both of which can have serious impacts on the health of humans, wildlife, and domestic animals.

Combatting these threats is an immense challenge that relies heavily on an integrated approach that includes investment in new medical treatments, diagnostics, and vaccines, as well as research into monitoring tick populations, reducing tick and host habitat, managing ticks and their wildlife hosts, and widespread educational outreach. Maine has been fortunate to have a relatively long history of research and outreach on tick-related issues thanks to a collaborative network of private and public institutions. The Maine Medical Center Research Institute has been conducting research on ticks and vector-borne disease since the late 1980's and has emerged as a leader in the field. Maine CDC has taken a proactive role, combining epidemiology with widespread public outreach efforts to help minimize the spread of tick-borne disease. Many states have stopped counting cases of Lyme disease due to the high burden placed on state health departments and have instead begun estimating cases. These estimates can vary in their accuracy, thus affecting the regional and national rates of disease. Maine CDC is still counting individual cases, but as the burden continues to increase and funding remains limited, a transition to an estimation system is likely.

At the University of Maine, significant research is underway both in the School of Biology and Cooperative Extension. A primary goal of UMaine Extension is to explore ways to minimize the occurrence and spread of ticks and tick-borne disease in Maine. Understanding the shifts in tick population size and geographic range is critical in evaluating risk and targeting management strategies. UMaine Extension currently monitors tick populations through a public tick identification program and tick-borne disease screening program. Through these programs, Maine residents can send tick samples to the lab for identification and to test whether the ticks are carrying the pathogens that cause Lyme disease, anaplasmosis, and babesiosis. Additional pathogens are scheduled to be added to the testing program in 2020. A small scale active surveillance program is also ongoing, in which ticks are actively monitored through field survey methods. Additional active monitoring of small mammal hosts is also ongoing. The information generated from these programs will allow us to track the distribution of ticks and tick-borne disease in Maine and to identify priority areas for targeting prevention and management strategies.

The University of Maine School of Biology and Ecology is currently investigating multiple avenues related to the ecology of tick-borne disease, including the environmental conditions that enhance disease transmission, the impacts of climate change and human land-use patterns on ticks, as well as the risks related to tick-borne disease in Acadia National Park and its potential effects on the tourism industry.

The public demands and political will to fight Lyme disease and other tick-borne illnesses are strong in Maine, however, as with many rural states, the funding to wage such a battle is limited. Nonetheless, the people of Maine prioritized this battle in 2014 when voters approved a bond referendum to create a new University of Maine Cooperative Extension Diagnostic and Research Laboratory. Following several years of intense planning and construction, the new lab opened in June of 2018. This high-containment facility brings together research on animals, plants, and arthropods within one biosecure setting and has greatly enhanced the University's diagnostic capacities. The construction of this facility has also broadened the University's collaborative efforts, facilitating collaborations between UMaine, Maine CDC, and Maine Medical Center.

Through the work being done at UMaine Extension, the University of Maine School of Biology and Ecology, Maine Medical Center, and Maine CDC, the state has a solid infrastructure in place to tackle the issues surrounding tick-borne disease. Historically, however, funding for tick-related research and particularly outreach and education has been a relatively low priority. The TICK Act will inject a much-needed investment into research and education and allow us to leverage existing infrastructure to fund novel approaches to monitoring and managing ticks and tick-borne disease.

Thank you again Senator Collins for the opportunity to speak today and I welcome any questions.

Testimony for TICK Act Field Hearing
Thursday, September 5, 2019
Sean McCloy, MD, MPH, MA
Medical Director, Integrative Health Center of Maine

Thank you Senator Collins, as well as to the esteemed members of this panel. I am honored to speak about my experiences and frustrations as a physician treating patients with tick-borne disease. No other illness has been as intellectually challenging to properly diagnosis and manage as Lyme. The more I learn about this disease the more questions I have, and the more I realize we have just scratched the surface of how complex the answers are. Hopefully your work on the TICK Act will move the research forward and provide more hope and more help to Mainers, and to the worldwide public health.

As a young resident at Maine Medical Center, I felt I was well-trained in the classic signs and symptoms of Lyme Disease. We were taught to look for the bulls-eye rash, the flu symptoms outside of flu season, the joint pain. Like my colleagues I treated these acute cases with a short course of antibiotics. However, I began to see more and more patients who didn't fit the typical scenario. They never remembered a tick bite, they never had a rash. Their blood testing was negative for tick-borne illness. They grew sicker and sicker despite seeing multiple specialists. I had to become a detective doctor to figure out how to help these people. I needed new tools for my tool box.

I began attending conferences run by the International Lyme and Associated Diseases Society (ILADS) and learned that there was more to the story than the basic model I was taught in medical school. I learned there were differing opinions and conflicting guidelines between the Infectious Diseases Society of America (IDSA) and ILADS. In short, IDSA states that Lyme Disease is easily diagnosed with standard two-step blood testing and easily treated with a short course of antibiotics. If patients' symptoms persist it is because of the damage already done and not because of a lingering infection. ILADS' view is just the opposite: the standard testing may not be accurate because of how Lyme can fool the immune system, and a short course of antibiotics may not be enough to eradicate all organisms in a person's body. ILADS feels that chronically ill individuals need a more comprehensive and long-term therapeutic regimen to treat their real disease, and not just be dismissed as suffering from "the aches and pains of daily living".

Here we had two groups of very smart doctors, both wanting to help their patients, at loggerheads over how to diagnose and treat Lyme Disease. This conflict left me and my patients in the middle searching for solutions. Now I've got a Master's in Public Health and a Master's in Medical Sciences so I love research. I dove into the literature from the standpoint of an open-minded skeptic. I read both sets of guidelines. I read the peer-reviewed journal articles supporting both sets of guidelines. I looked into who the authors were and who was paying for their research. In the end, I tried both sets of guidelines on my real-life patients to observe which approach worked best.

I found there was room for both the IDSA and ILADS solutions depending on the situation. The IDSA approach works well for acute, classic Lyme Disease. If a person has a strong, healthy, robust immune system at baseline then the testing should begin to turn positive after 2-3 weeks of infection. Fortunately this infection is usually very easy to treat with a short course of antibiotics *if you catch it early.*

Unfortunately, if you don't catch it early, this smart little spirochete begins to go through its own life cycle. It changes its shape and hides from the immune system, causing inaccurate, false negative blood testing. It creates a physical barrier called a biofilm that protects it from antimicrobials and from your own white blood cells. We are discovering what are called 'persistor cells' that are resistant to antibiotic therapy. They can remain dormant in a human body for months or years before they wake up again.

In the unfortunate individuals who become chronically ill, multiple systems are affected. There is a complex interplay of genetic factors, inflammation and immune dysregulation, hormonal imbalance, neuroendocrine disruption and neuroinflammation leading to cognitive deficits and psychological illness, gastrointestinal dysfunction causing nutritional insufficiencies, which create metabolic imbalance and poor mitochondrial function, leading to the chronic fatigue that many describe. As I learned, a few weeks of antibiotics are not enough to heal these complex cases.

The ILADS approach works better for these types of patients. It is an individualized, head-to-toe, integrative method of figuring out what is broken, what are the root causes of the illness, and how to help that person heal from the inside out. It's certainly not a perfect approach. Sometimes it requires long-term antibiotics that have their own risk of side effects. It's complicated and it takes a lot of the practitioner's time to do the detective work. It also takes a lot of the patient's time and energy and healthcare dollars to walk that road to recovery. These people need a lot of support to get them through the bad days. Eventually they celebrate more and more good days and move forward to remission.

To summarize, I have learned that there is no perfect set of guidelines, no one-size-fits-all algorithm that works for every case in the real world. The testing is imperfect. The medications don't always work. Some people get better right away, and some people develop problems that linger for years. The classic presentation of Lyme Disease that physicians learn about in medical textbooks doesn't always apply, because this little bug forgot to read the textbook.

We need more answers, Senator Collins. How can we prevent the illness in the first place? How can we improve the accuracy of the testing? How can we tell which treatments will work best, and how do we know when to discontinue a regimen? Your excellent work with the TICK Act will hopefully help provide more answers to the doctors and patients out there dealing with tickborne disease. Thank you very much and be well.

Paula Jackson Jones
Field Hearing Testimony – Orono, Maine
Sept 5, 2019

Chairman Collins,

Thank you for holding this hearing and for inviting me to testify today. My name is Paula Jackson Jones, and I am here to share my story and my life's work. This has been a 10-year crusade for me, with the first 5 years fighting for my life and the latter fighting on behalf of others.

I was bit by a tick in October of 2009 while outside doing fall clean up with my husband. At the end of the day, while cleaning up, I discovered a tick embedded in my side. We removed it, flushed it and never gave it another thought. Not even when I became systematic 10 days later. For the next 2 years, I was misdiagnosed by 23 doctors and specialist with everything from panic attacks to respiratory infections, chronic fatigue to fibromyalgia. When a scan revealed lesions on my brain and my neurological symptoms intensified, I was tested and diagnosed with MS. When my symptoms became even more severe and I was not responding to treatment, I was re-evaluated and my diagnosis changed to Parkinson's. When I got lost driving, my doctor revoked my license and when I began to have trouble swallowing and the use of my arms and legs was a daily challenged, my medical providers wanted me tested for ALS. I knew that was a death sentence for me and it was at this point I knew that I needed to fight and advocate for myself.

Thanks to a family member who kept pressing me to be checked for Lyme disease, even though I had 4 negative tests, I demanded to see a provider who knew about Lyme. My primary doctor refused to give me a referral because that was not what they thought I had. However, the intern gave me a scrap of paper with the name of someone he knew who saw Lyme patients and that doctor, a Maine doctor, number 24, saved my life.

In April 2011, after clinical examination, additional bloodwork and tests, I was diagnosed with late stage neurological Lyme, Babesia, Bartonella, Rocky Mtn Spotted Fever and Erlichiosis. That medical provider, who knew more about Lyme and tick-borne disease, not only saved my life but gave my life back to me.

When a cancer doctor thinks outside the box and heals their patient, they are deemed a hero. When a Lyme provider does it, they are brought up under medical scrutiny and disciplined beyond belief.

The Infectious Diseases Society of America (IDSA), the governing body that exists and controls all things to do with disease wrote in their guidelines a foot note that reads as follows:

"These guidelines were developed and issued on behalf of the Infectious Diseases Society of America.

It is important to realize that guidelines cannot always account for individual variation among patients. They are not intended to supplant physician judgment with respect to particular patients or special clinical situations. The Infectious Diseases Society of America considers adherence to these guidelines to be voluntary, with the ultimate determination regarding their application to be made by the physician in the light of each patient's individual circumstances."

My treatment was not conventional or mainstream but it was effective. It was tailored to my infections and to how I was responding. Thankfully, my medical provider had a vast amount of resources to turn to when treatment options failed. And in April 2014, I went into remission. Today, I remain in full remission going on 5 and a half years. Although faced with a mountain of medical bills not covered by insurance to the tune of $250,000, I am thankful every day for my health. Others have not been so fortunate. Misdiagnosis leads to a life riddled with pain, robbed of joy, floundering from lack of support and struggling just to be heard and validated and that's if the disease doesn't take your life in the process.

In April of 2014, after going into remission I wanted to make a difference where I lived. I wanted to help raise awareness about the risk of tick-borne disease and educate people on how to protect themselves. But more importantly, I wanted to make their search for resources not only easier to find but accessible and affordable. I co-founded and became President of Midcoast Lyme Disease Support & Education (MLDSE). We are a charitable nonprofit 501c3 organization that travels statewide, hosting year round free educational and prevention talks and events. We advocate for change at state and federal levels and provide support to those in Maine afflicted by tick-borne disease by connecting them to medical providers, educational and financial assistance programs. We are the Maine partner of the national Lyme Disease Association, members of Maine's CDC Vector-borne Work Group and active in Maine's Lyme legislation. We are members of the worldwide Ad-Hoc Patient-Physician Coalition consisting of 67 organizations from 6 countries who are concerned that the proposed Lyme disease guidelines of the Infectious Diseases Society of America (IDSA), American Academy of Neurology (AAN), and American College of Rheumatology (ACR) will further restrict access to care and harm patients by leaving them undiagnosed and undertreated. The coalition consists of over 35 patient groups, (including LymeDisease.org, the National Lyme Disease Association, Bay Area Lyme Foundation among others) and the International Lyme and Associated Diseases Society, which represents clinicians who treat Lyme disease nationwide.

In 2018, I served as the co-chair to the Federal Health & Human Services Tick-borne Disease Working Group's Access to Care Services and Patient Support subcommittee. Our role was to identify gaps and barriers that patients faced in accessing proper diagnosis and treatment. That information went into a report presented to the federal TBDWG, who compiled all subcommittee reports into a report to Congress. I was honored to have been selected for that role as it defines who I am these days, sitting in the trenches alongside patients and their families and connecting them with whatever services they need as they journey back towards health and wellness. I am not a victim but a survivor and one who advocates for those who cannot advocate for themselves. A fulltime job for and one that I do year round and on a voluntary basis without pay.

Lyme and tick-borne disease is not a cookie cutter disease and yet, the cookie cutter approach has failed time and time again.

It has been acknowledged at a federal level that current Lyme Disease testing is, at best, 25-40% reliable. It is less accurate in acute cases because providers test too soon, and patients may not have produced antibodies. Also, more physician education is needed to determine just what test is warranted. In an April 1, 2018, National Institute of Health article "Advances in Serodiagnostic Testing for Lyme Disease Are at Hand" it was concluded that "for the past 2 decades, the concept of a 2-tiered strategy aimed at high sensitivity and specificity has been widely used, but the current approach is insensitive during the first weeks of Lyme disease, and Western blotting can be complex to perform and interpret."

Then, in a July 25, 2018 National Institute of Health article "Tick-borne Diseases Are Likely To Increase", there were several points mentioned that caught my eye:

- The incidence of tick-borne infections in the United States has risen significantly within the past decade.

- It is imperative, therefore, that public health officials and scientists build a robust understanding of pathogenesis, design improved diagnostics, and develop preventive vaccines.

- Tickborne virus infections are also increasing and could cause serious illness and death.

- The public health burden of tickborne disease is considerably underreported, according to the authors. According to the authors, this is due in part to the limitations of current tickborne disease surveillance, as well as current diagnostics, which may be imprecise in some cases and are unable to recognize new tickborne pathogens as they emerge.

It was suggested:

- By focusing research on the epidemiology of tickborne diseases, improving diagnostics, finding new treatments and developing preventive vaccines, public health officials and researchers may be able to stem the growing threat these diseases pose.

So faulty tests are identified and the need for more physician education is imperative to curtailing this growing epidemic. This is where passing the TICK Act Bill into law will provide a lifeline not only to patients but to medical providers. With funding available for research and education, we can get medical providers on the same page not only with better diagnostic tools but better, more effective treatment options for their patients.

[See Appendix A: The Ad Hoc Patient and Physician Coalition Comments of the IDSA Proposed Lyme Guidelines]

Link to Article 1 [Read the full article here: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6019075/]

Link to article 2 [Read the article in full here: https://www.niaid.nih.gov/news-events/tickborne-diseases-are-likely-increase-say-niaid-officials?fbclid=IwAR3spS7ypl7xgr6l1YLsVH_XDJZoXsfOaAceDVh72myTxhM-boQhxJVrSp0]

Testimony of Christopher Philbrook
Before the Special Committee on Aging's Field Hearing
Orono, Maine
September 5, 2019

It's a small thing, but I didn't realize how important smiling was to my mental health until I couldn't do it anymore.

On a Saturday afternoon in 2007, I took a trip to Hogback Mountain in Virginia. Shortly after that trip, I woke up incapacitated. I could barely move a muscle. I thought I might have the flu, so I stayed in bed and did not think much of it at first. But I've always been healthy and quick to recover, so when my condition did not improve in a few days, I flew home to Maine to see my doctor.

One problem with Lyme disease is that the symptoms mimic so many other things, as I would soon discover.

When I got home, my 7th cranial nerve, which runs down the left side of the face, went into a state of trauma. In addition to the flu-like symptoms, I now also had Bell's palsy. I also couldn't eat or sleep for days, and was in a state of pain so debilitating that I went to emergency room and received a CAT scan. The scan showed nothing abnormal, so the doctor suggested I see a neurologist.

I also scheduled a dentist appointment to see if something was wrong with my teeth, because they hurt badly. The dentist took one look at me and said, "Bell's palsy can be the result of Lyme disease. Do you have a tick bite or bullseye rash?"

I didn't.

But I mentioned this to my neurologist, and he tested me for Lyme.

The test came back negative.

Shortly after that, the right side of my face went into paralysis. I now had Bell's palsy on both sides of my face, and the neurologist recommended an MRI.

That MRI showed what looked like a tumor either blocking or growing on my cavernous sinus, a nerve that runs from the brain to the face. We started talking about surgery and radiation.

Now I'm starting to worry.

Next, the neurologist recommended a spinal tap. If you've never had a spinal tap, consider yourself very lucky. It's awful.

The neurologist also ordered a second MRI, this time injecting a blue dye into my body so the tumor would show up in greater detail. He also ordered a chest x-ray because I was having trouble breathing.

The spinal tap showed Lyme in my spinal fluid, and the blue dye showed that the disease had attacked the nerves in my brain, causing extreme inflammation.

But, the good news? I didn't have a tumor.

I did, however, need to have a picc line installed immediately. For four weeks, the line delivered a strong dose of antibiotics from my bicep to my heart.

I was working on Senator Collins' staff at the time, and she watched my pain and suffering first hand. I still have daily notes from her checking in on me. One said, "you gave us quite a scare."

It *was* scary. And it remains scary to know that ticks carrying Lyme are a constant threat in my own backyard. With its proposed private-public partnerships including pest control, the TICK Act aims to alleviate that threat – a prospect that would relieve a lot of anxiety for anyone who has been through this disease.

I was lucky that my dentist spoke up, that I had a spinal tap (not a normal Lyme testing protocol), and that my Lyme disease was treated quickly, within the first month and a half. I'm happy to say that after my antibiotic treatment, I was cleared of the disease, although residual effects remain – mainly sleep disturbances and facial paralysis.

Others are not so lucky. When Lyme is not diagnosed quickly, co-infections can develop and the disease can become much more difficult to treat. This happens far too often, which is why the TICK Act's directive for improved diagnostic testing is so important.

For my ongoing symptoms, the most effective relief has come from food. After eight years without improvement, and having been told the only solution was plastic surgery, I started on a ketogenetic diet and intermittent fasting – something author Tim Ferriss said was the only thing that knocked out his Lyme disease. Within seven days, I felt movement in my face that I hadn't felt in years. Because ketosis is unrealistic for me to maintain long-term, I've fallen back on Tom Brady's eating and training regimen, the TB12 method. While this approach may not work for everyone, it has kept my symptoms at bay. The problem is, my story doesn't scale – I heard about this approach by chance on a podcast. Conversely, the TICK Act would create database where treatment approaches and outcomes could be shared immediately in the context where it matters most – the doctor's office.

Thank you, Senator Collins, for this opportunity and for your work on this public health threat. I hope the TICK Act, when enacted, gives people currently suffering with Lyme disease validation and hope that they can and will get better.

Statements for the Record

Holly Noonan, Camden Maine
Testimony for the Record

My name is Holly Noonan and I am a 48 year old Social Worker who lived in Camden, Maine for 17 years. In 2016, I became an environmental refugee and was forced to leave my home and my son in Maine. I became unable to stay inside any building for more than a matter of minutes. I joined the throngs of men and women living in their cars to regain their health around this country, mostly out west --if they can get there. I have met dozens of other people with my plight in person and thousands online. We are a family that you never want to join.

Each person has a different presentation but with the same constellation of problems. Lyme disease and coinfections that led to mold sensitivity, then extreme chemical sensitivity and lastly they can develop sensitivity to EMFs or electromagnetic frequencies. These chronic, disabling illnesses have many unique layers that impact those who have a genetic vulnerability to them. It is not our fault.

In order to regain my health to the level that I can attend your Field Hearing in Maine, I have had to do unfathomable things and a gargantuan amount of work. I left Maine not knowing where I was going. I was simply looking for a place that didn't make me sick. I found a tiny village surrounded by a 3.3 million acre wilderness in New Mexico with air that is still as clean as 100 years ago. It was a challenge to find a place this clean in America.

I stayed there, in virtual outdoor quarantine, for 12 months-- January to January. During this time, if I was in proximity to tiny amounts of chemicals or mold, my body would go haywire. Complete inability to sleep, internal tremor, diarrhea, headaches. My lungs would hurt then all my organs would swell up and hurt. (This still happens and is happening today.) I was too sick to even sleep inside my car so I slept in a hammock in the wilderness over 2 winters. The January I left, I had healed enough to be inside a clean building part of the time-- but I still sleep outside now.

I met several other environmental refugees there. One woman was so sensitive to chemicals and EMFs that even being in this pristine wilderness village was difficult so she drove up into the mountains every night to sleep in her truck. When the village installed 5G routers, she had to leave this place too.

The underlying culprit seems always to involve tick-borne illnesses. The numbers you quote as to how many people are dealing with tick-borne illnesses is vastly under-estimated. You are not accounting for all the people whose doctors tell them "I can't find anything wrong with you." and slip beneath the collective awareness into their own wandering, personal hell.

Since there is an utterly inadequate system for diagnosis and a political controversy around Lyme disease and co-infections, there are vast numbers of sick people who have dropped beneath the threshhold of functioning that is required for self-advocacy. The energy that is required to puncture the enormous obstacles in the way of diagnosis and treatment means this: You don't have accurate numbers.

In the spring of 2019, I sent my blood and the blood of my client-- a disabled Vet-- to Armin Labratories in Germany. Armin is only one of two labratories in the world that can be trusted to deliver accurate diagnoses for tick-born illnesses. Not only was it cheaper to send our blood out of the country, the tests they offer are more accurate. They offer a wide range of T-cell testing-- a technique developed to diagnose Tuberculosis.

Given that one of the actions of parasitic, intracellular Tick-borne bacteria is to *suppress antibody production,* Dr Armin Schwarzbach looked for-- and found-- a way to test without relying on finding antibodies. He calls it Elispot and it is 200x more sensitive than antibody testing.

The results came back. I had 3 tick-borne infections (including Rickettsia) and my client who is a vet had 2 tick-borne infections including borrelia-- or lyme disease.

For me, this has been a 17 year medical mystery since I went to an infectious diseases doctor in Rockport, Maine in 2002 who had no idea what I was dealing with. Now I know.

For my client, I watched the VA bumble and obfuscate his expensive medical treatment but NEVER TESTED FOR LYME for 15 years even though he reported multiple times that he had had an embedded tick with a bullseye rash, which is all the information you need for a positive diagnosis.

Given the information delivered to the public in the book "Bitten," by Kris Newby, I would like to ask you directly if it is a policy of the Veterans Administration to avoid testing for lyme disease? The amount of disability and suffering this veteran has experienced has been egregious and unnecessary. He is now getting the correct treatment and is starting to feel better.

I am starting to regain my capacity to be helpful for other people now that I am also finally getting the correct treatment.

The process for diagnosis and treatment for tick-borne illnesses needs to radically change in the United States of America. Especially if the Federal Biological Weapons Program has any responsibility at all for causing this epidemic. Please investigate.

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Written Testimony of Dr. Kristen Honey, Ph.D. P.M.P.
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Hearing of the U.S. Senate Aging Committee:
The TICK Act: An Urgent Public Health Response to Tick-Borne Diseases

Orono, Maine | September 5, 2019

Ticks don't care if you're Republican or Democrat, so today's exponentially growing problem with Lyme disease warrants attention and priority from all of us. This mysterious and often misunderstood "invisible illness" takes an enormous toll on individuals and society.

DISCLAIMER: I share my personal experience as a constituent who contracted Lyme disease in Maine. By profession, I am a Stanford PhD scientist who has served in the White House for both Republican and Democratic administrations. This testimony, however, reflects my individual experience and personal opinion only; it does not reflect the views of the White House, U.S. Department of Health and Human Services (HHS), or any other federal agency where I have worked.

Chairman Collins, Ranking Member Casey and distinguished members of the Committee, thank you for the opportunity to provide written testimony about my personal experience with Lyme disease.

THANK YOU, MAINE

My Lyme disease story is not unusual, other than I was one of the lucky ones to achieve remission.

I'm grateful to the Maine taxpayers who subsidized my Lyme disease recovery. When at my weakest and most vulnerable, Maine provided the safety net. The Maine Department of Health and Human Services gave me food stamps, public assistance, and MaineCare insurance coverage to help me back on my feet. I was one friend away from homelessness, and my Maine community provided a home.

Literally, Maine saved my life. Thank you.

LYME DISEASE TODAY = LIFE-RISKING DESPERATION

Healing from late-stage Lyme disease was the most difficult challenge I've ever faced.

Lyme disease was the very-worst low of all my life's lows. I've experienced suicide loss and rape, and my diagnosis of PTSD trauma due to Lyme disease and how today's medical establishment treated me (and failed to medically treat me) equaled this emotional pain. I climbed Mount Kilimanjaro and summited its 19,341-foot Uhuru Peak; fatigue and exhaustion from Lyme disease were worse. I passed kidney stones; pain from Lyme disease hurt more. I've not given birth to children, yet friends who are mothers say their Lyme pain rivaled the pain of childbirth — without the positive outcome to make extreme pain worth it.

Today's situation with Lyme disease is dire. Lyme patients, myself included, are being failed by a broken U.S. medical system. In the wake of insurance claim denials and antibiotic treatments withheld, Lyme patients are left to fend for themselves. This leads to desperate measures.

Patients self-treat with untested, and often risky, protocols that could kill. Others opt to die and take their own lives by suicide to escape the pain, desperation, and hopelessness with Lyme disease.

I am only one individual anecdote among 300,000 new U.S. cases each year, plus millions of others who are struggling with chronic Lyme and complex tick-borne diseases. I relay my experience as an individual citizen. I am a Stanford PhD scientist, yet these words are not those of Stanford University. I have worked in the White House and the U.S. Department of Health and Human Services (HHS), but these words do not represent federal government. This is my story.

FROM STANFORD PHD… TO FOOD STAMPS… AND BACK!

Maine is where I contracted Lyme disease in 1999 on Long Island in Casco Bay. That summer, dozens of ticks bit me. After these tick bites and experiencing what I thought was a summer flu, my health changed. My doctors and I never suspected Lyme disease, since we never saw an erythema migrans rash (i.e., bullseye rash). Years later, we know not everyone with Lyme disease will get a bullseye rash.

For nearly 10 years after these tick bites, my health declined as I went untreated. Undiagnosed Lyme disease masqueraded as unusual symptoms and seemingly unrelated ailments including (but not limited to): adjustment disorder, adult-onset acne, adult-onset ADD/ADHD, anxiety, depression, early-onset rheumatoid arthritis, Hashimoto's disease, headaches, insomnia, plantar warts, Raynaud's disease, suspected Lupus (tests negative), suspected mononucleosis (tests negative), tachycardia, and toe fungus. Acne was a "lucky" symptom because this diagnosis led doctors to prescribe 6+ years of Minocycline 200mg 2x/day, which is in the same antibiotics class as Doxycycline used to treat Lyme disease. It's plausible that long-term antibiotics use for acne inhibited the Lyme-causing bacteria… temporarily.

In 2009, during the final year of my Stanford University PhD program, I opted to discontinue long-term antibiotics for acne because of emerging research on the microbiome and good gut health. Symptoms worsened. Doctors dismissed my worsening symptoms as stress-related and advised me to stop working so hard. After discontinuing minocycline, I collapsed completely.

In late 2009 — a full 10+ years after my tick bites in Maine — clinicians with the Stanford University Lyme Disease Working Group diagnosed me with late-stage, neurological Lyme disease. However, the Stanford University infectious disease department refused to treat me for Lyme disease. This forced me to go outside the Stanford hospital system and pay out-of-pocket for Stanford-affiliated doctors. These doctors gave me a two-year recovery plan, assuming 100% full-time healing. I couldn't work. I quit school.

Being too sick to care for myself and live independently, in 2010, I moved back in with my parents in Portland, Maine, at the age of 35. Lyme disease affects not only the individual patient, but the entire family system. The stressors of living with Lyme disease are immense.

Financially, Lyme devastates: My experience was typical: I lost my medical insurance coverage when I quit school. Patients like me become too ill to work. Even with insurance (if one still has insurance after losing a job), insurance companies often deny Lyme treatments beyond 2-4 weeks of antibiotics. This

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forces Lyme patients — an extremely vulnerable population — to pay out-of-pocket or forego treatment. Treatment denied or delayed results in Lyme disease progression, so patients grow sicker and sicker with diminishing chances of recovery over time.

In my experience, out-of-pocket Lyme expenses totaled approximately $250,000 over three years for me to regain my health (health sufficient to work again). Expensive, yes — incredibly expensive. Lyme destroyed my financial security and American dream, yet I'm alive. Many others are not so fortunate. I am part of the "lucky" minority who could liquidate assets for health. I sold my house, depleted my life savings, cashed in retirement plans, and drew upon years of excellent credit in order to fund medical treatments with credit card debt. Today's landscape with Lyme disease reminds me of HIV/AIDS in the 1980s when "wealthy" patients — or those with means to refinance houses, sell possessions, and access credit lines — went off label to pay for their own risky treatments.

My anecdote is only one example; the full economic and societal costs from Lyme disease are unknown. Preliminary cost-of-illness estimates suggest that Lyme disease drains the U.S. economy tens of billions of dollars each year. Economists have not yet fully characterized societal costs including indirect costs from Lyme disease, for example: lost wages/productivity, Medicare/Medicaid, Social Security disability insurance (SSDI), military family and Veterans benefits, military readiness, special education like individualized education programs (IEPs) related to Lyme disease, and American lives lost. No doubt, costs are staggering.

Physically, Lyme erodes quality of life and independence: Tachycardia of 180+ heart beats per minute concerned doctors, yet my symptoms were largely subjective and hard to measure: fatigue, pain, migraines, light/sound/chemical sensitivities, brain fog, and complaints not apparent to the eye. Family and friends would often say, "but you don't look sick." Strangers would sometimes leave nasty notes on my windshield, erroneously assuming that I was abusing a handicapped parking permit. Once, a police officer stopped me in handicapped parking and demanded medical documentation to prove a disability. When I showed my permit paperwork with medical justification, this officer advised me to keep this paperwork on hand, saying that I'd likely be doubted and stopped again. True. Day-to-day errands proved trying and more exhausting than necessary. Grocery store baggers sometimes laughed when I requested help, assuming I was joking since I looked healthy. When traveling in airports, I was harassed by airline employees who doubted my medical need for early boarding.

There's an irony to looking well, while physically you're the opposite of well. Such dismissal by U.S. society and mainstream medicine can lead to death. Untreated infection not only physically debilitates but, in rare cases, can also be fatal when Lyme-causing bacteria affects heart tissue (i.e., Lyme carditis).

Emotionally, Lyme destroys families and relationships: The financial burden and stress of Lyme disease often extends to family and friends. Few relationships survive it. In my family, Mom provided the emotional support and love — as well as financial and medical support — for my Lyme disease recovery. Mom had been trained as a nurse, so had the knowledge and medical curiosity to understand the complex facets of this disease. Nonetheless, my late-stage, neurological Lyme disease caused familial stress. Mom ran interference and supported me, when other family members doubted the validity of the Lyme diagnosis.

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While I was living at my parent's home focused on my Lyme recovery, my Mom took her life by suicide. Perhaps the familial stresses from Lyme disease were too much. Grief overwhelmed my recovery plan. Grief tore apart the Honey family, including my support network. Amidst a family shattered and a medical community divided on how to treat or acknowledge Lyme disease, I was left alone to navigate myself back to health. This suicide loss added new trauma and shock, extending my Lyme disease recovery process.

Ultimately, it took 2.5 years of full-time healing from Lyme disease before I could live independently and work full-time again. My story differs only because I achieved remission, which is all too rare for late-stage, neurological Lyme disease.

21ST-CENTURY DALLAS BUYERS CLUB

I fell through the cracks of a broken medical system, as so many Lyme patients do.

My case is noteworthy because, as a scientist, I pioneered an off-the-books experimental treatment. I used myself as a guinea pig by augmenting pulsed combinations of oral antibiotics with intravenous (IV) nanominerals including nanosilver and nanogold. Risky, yes. Extremely risky.

I was fortunate to have a professional network of world-class biologists and Stanford University researchers who were willing to help me navigate the complex science and experimental treatment options. This scientific access — combined with my adventurous personality and confidence — empowered me to take calculated risks that others might judge overly risky. I found myself in a desperate situation, facing a lifetime of pain and symptom management without quality of life. Alternatively, I could try something different and face unknown risks, potentially death, without any guarantee that it could ameliorate neurological Lyme disease. It was an untenable situation for someone bed-ridden with "Lyme brain" as I was. Based on limited scientific information, which included input from Stanford microbiologists and experts, I chose the unknown. I gambled on an untraveled path.

No doctors would administer the experimental IV treatments. This forced me to watch YouTube videos on phlebotomy and self-treat. Untrained, I administered my own IVs.

To live, I had to go outside the bounds of FDA-approved treatments. This is scary. It is unsafe. It poses huge risks, both financial and physical risks to vulnerable patients.

No patient should ever have to self-treat like this. Even when trained doctors treat neurological Lyme disease, they use off-label drugs and non-FDA-approved treatments. There are no other alternatives.

We're amidst a "21st-Century Dallas Buyers Club" with Lyme disease.

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BEYOND LYME DISEASE, PAYING IT FORWARD

Given experimental treatments to augment oral antibiotics, my unique case of Lyme disease resolved after 2.5 years of full-time healing. As a Stanford scientist with PhD-level understanding of biology, I'm dubious that I'll ever be 100% "cured" of Lyme disease; rather, my body and immune system likely co-exist with the Lyme-causing bacteria.

I suffered a Lyme disease relapse in 2017, without any new tick bites, which seemingly affirms the coexistence hypothesis. After 6 years remission, I again went on oral antibiotics augmented by IV nanomineral treatments for approximately one year. During this 2017 and 2018 relapse, I presented with a bullseye rash—19 years after my original tick bites—so there was no doubt it was Lyme disease.

Whether I'm cured or coexisting with Lyme disease, today, I aim to "Pay It Forward" to help others with my renewed health. Healing from Lyme disease and thriving in life will look different for everyone. There is no silver bullet. There is no one path to Rome. Each individual's experience with Lyme disease is unique, yet we can help one another by sharing wisdom gained along the way.

Paying it forward includes openly sharing my Lyme disease story. Too many struggle in silence. They are not alone. There is hope. Recovery and remission are possible. I'll close with a personal mantra that helped me and I hope these words will also support the recovery process for other Lyme patients:

Rest. Breathe. Sleep. Pray.
Accept. Surrender.
Heal.

Hope is necessary, but is insufficient alone. We must transform anecdotes like mine into action.

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Testimony of Joel Beaule
09/05/19

Dear Senator Collins,

My name is Joel Beaule and I am writing to you today to share my experience with chronic Lyme and to fully support your efforts in securing additional funding for research and treatment options of tick borne diseases through the TICK Act.

As with some of the people afflicted by this terrible disease, my experiences with suffering from Lyme Disease and associated co-infections began with a series of symptoms including the telltale bullseye rash in July of 2013. Within four days of noticing the rash, I began receiving treatment for Lyme disease based upon the CDC guidelines. This treatment lasted for 3 weeks but unfortunately it did not relieve my symptoms in any way shape or form. Suffice it to say, I have chronic Lyme disease (or as the IDSA prefers to call it Post Treatment Lyme Disease Syndrome) and have been battling this disease for the last six years. My symptoms are many and include a constant tingling on the left side of my face, burning throughout my body, flu like symptoms, vertigo and what is called “brain fog”. It would be an understatement to suggest that this disease has completely turned my life upside down. This said, it is without question that long term antibiotics have allowed me to function and return to work, so that I may pay my bills and attempt to lead the life that I used to have before becoming sick.

I want you to imagine what it would be like to be living your life as you normally would and then one day you wake up and your very sick, sicker then you have ever felt. As time moves forward, you become more debilitated and you cannot go to work. After several weeks, your employer calls you and tells you that unless you can get a letter from a doctor indicating you have Lyme disease then you will be terminated. You have a mortgage, bills, and people that depend on you for stability. As many doctors do not recognize chronic Lyme disease, you desperately scour the internet and seek help from area doctors to see if they will treat you. Unfortunately, no one will. You therefore go from one specialist to the next and they suggest that you have Lupus, Multiple Sclerosis, Bells Palsy, Parkinson’s, or perhaps that it’s all in your head. Unbelievably, you cannot find a doctor that is willing to treat you because according to the CDC, chronic Lyme does not exist. This is the nightmare that patients with tick borne diseases live with on a daily basis.

Senator Collins, I am encouraged by your efforts in securing additional funding for research and treatment. As I have been living with this disease for more than six years, I have many thoughts on this subject and would be happy to speak with you directly or a member from your office. Please feel free to reach me via email (joelbeaule@hotmail.com) should you have questions or require additional feedback on this topic.

Thank you for your time and consideration.

“In the fullness of time, the mainstream handling of Chronic Lyme disease will be viewed as one of the most shameful episodes in the history of medicine because elements of academic medicine, elements of government and virtually the entire insurance industry have colluded to deny a disease.”

- Dr. Kenneth Liegner

September 5, 2019

Testimony in support of the *Ticks: Identify, Control, and Knockout (TICK) Act.*

My name is Michaela Cisowski. I am a senior at the Univerisity of Maine studying zoology with a concentration in pre-medical studies. I am here today to voice my strong support for Senator Collins's and her team's *Tick Act*.

Lyme Disease was discovered in the 1970s when it was mistaken for juvenile rheumatoid arthritis. It was unexpected that this misdiagnosis would turn into one of the saddest epidemics in medical history. The majority of chronic Lyme patients are infected with at least one co-infection as well. Some of the common co-infections include Babesia, Bartonella, Ehrlichia, Mycoplasma, Rocky Mountain Spotted Fever, Anaplasma...the list continues and new tick-borne pathogens are still being discovered.

Looking at the spirochete bacteria, it is a rather brilliant bacteria based on the limited research that we do have. Once it enters the body, it infects the cells and releases a coagulating protein substance that turns into a "biofilm." This biofilm provides protection to the spirochetes from antibiotics and the immune system. This can lead to antibiotic resistance. At maturity, the bacteria disperse from the biofilm and release into the body. The bacteria itself is shaped like a corkscrew. It physically "screws" its way into its host's tissues, muscles, joints, and organs. This technique is what causes arthritic pain, and stiff/sore muscle aches.

This cringing image is something that I experience on a daily basis. I was diagnosed with Lyme Disease, Bartonella, and Babesia in July of 2017 and it has affected nearly every aspect of my life since. I have seen 3 Lyme specialists, 2 naturopathic doctors, 1 homeopathic chiropractor, 1 Lyme nutritionist, 1 cardiologist, and 4 mental health practitioners. I have had several visits with my PCP to discuss anxiety/depression, specialist referrals, cardiac complications, and reoccurring UTI symptoms. In total, I have treated with 8 different antibiotics over the course of 15 months, and several herbal protocols over the course of 10 months. I am currently treating again with another round of antibiotics. Over 27 months, myself and my family have accrued $16,000 for these medical bills. This does not include the excess money that I spend on groceries to purchase healthy food to support my immune system or food that I can tolerate while on antibiotic treatment. Nor does it include the cost of classes at the university that I have had to retake due to relapses that have inhibited my ability to perform to the academic abilities I held prior to my illness. But most importantly, that $16,000 does not represent the diminished quality of life that myself and my friends and family have experienced because of my illness.

You may ask me why I am considered lucky? I was lucky to be diagnosed early and given a 3 week initial round of Doxycycline, which is in line with the CDC guidelines and considered a cure. I am living proof that Lyme may not be cured with a round of Doxycycline, even if caught in the early stages. After my second round of antibiotics, I thought that I was well on my way to recovery. I packed up my things and moved back to school in Orono. Little did I know that it would be the worst semester of my college career. After being on campus for 3 weeks, I had allergic reactions to all of my medications. I went to class covered head to toe in hives, with a low-grade fever, swollen face, and absolutely exhausted. My doctor promptly switched me to three new antibiotics that had side effects that were nearly as bad as my Lyme Disease symptoms. I was unable to drive because I was so off-balance from them. I could not concentrate because of brain fog. I was so sick and I was over 6 hours from my support team. I had a close friend at the time who insisted on coming and sitting at my desk while a napped on some of my worst days. He had his keys with him and checked on me constantly, ready to take me to the hospital. But I stuck it out because I wanted to be in school like everyone else and I did not want to get behind. Over the next two years, I relapsed 4 times after I was told that I was in remission. I failed a class and had to retake it because I was unable to keep up. I was put on antidepressants and started to go to counseling because of the emotional effect this was having on me and the hopelessness that I felt on a daily basis. I then started having cardiac complications. I could not stand for more than 5 minutes at a time without experiencing palpitations and lightheadedness. I couldn't make it through a workday without feeling like I was going to pass out. Now imagine someone that you know, a daughter, a son, a granddaughter, grandson, niece, nephew...calling you daily, crying because of how much pain they are in. Explaining all of these horrible days and how they want to give up. This was my mom and dad. My mom would cry for hours after hanging up the phone with me, and I had no idea. This took a significant toll on my family.

I lost friends. I stopped getting invited to go out. It's tough being at this age and having an invisible disease that no one can see or feel except you. They didn't understand. I had nights where I had to cancel plans because I was too drained from going to classes. I almost lost my job too because I had a lot of call-outs from mornings where I couldn't get out of bed, couldn't dig my car out of the snow, or could not walk because my joints were so swollen. It's easy to assume that a college student is calling out because they are hungover, stayed up too late studying, or would have rather spent the day at the beach or skiing. But I didn't. I was in bed.

My father was diagnosed with Lyme Disease and Babesia 14 years ago and there has been little to no improvement treatment wise. Lab tests are unreliable creating extended pain, suffering and financial hardships. It is 2019. Lyme Disease has been around since the 1970s. This is unacceptable. I had a friend from high school reach out to be about a month ago saying that he tested positive for Lyme Disease. He was given 1 month of Doxycycline. He was miserable texting me every day complaining of symptoms that I knew all too well. And it broke my heart that I did not have answers for him because I did not even have them for myself. We need better treatments. We need more education. Is this disease sexually transmitted? Will I pass this along to a child if I become pregnant? Can my body withstand a pregnancy without making me sicker? Can I donate blood? Can I be an organ donor? Are there screenings for Lyme Disease and associated co-infections for organ donors and blood donors? Would you want my blood or organs?

This *Tick Act* is important because, in the long run, it will help individuals like myself find effective treatments and are hopefully more affordable. It will help establish nationwide resources and grants to improve research, diagnosis, treatment, and public awareness and education. It will help those who do not look sick, but are suffering inside.

I applaud Senator Collins and her team for bringing forth this legislation and I respectfully urge you to support this very important legislation.

Thank you Senators Collins and Smith for co-sponsoring this bill.

Michaela Cisowski
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Maine Medical Center
MaineHealth

Dear Senator Collins, September 13, 2019

On behalf of the Maine Medical Center Research Institute Vector-borne Disease Laboratory and Divisions of Infectious Diseases at MMC, we are writing in support of the proposed Tick Act. As Maine board certified infectious disease physicians who have been directly involved in efforts for tick- borne disease prevention, diagnosis and treatment, we hope to share our professional perspective on both the need and the opportunities in Maine to contribute to the science and assessment of efforts to prevent and treat these diseases.

Starting with the first case reports of Lyme disease in Maine in the 1980s, we created a research program based at Maine Medical Center to track the advance of tick borne diseases and to study the factors that lead to increased risk for this disease in Maine, as well as initiating and assessing community based efforts to decrease disease risk. Our efforts on the latter front included the proof of principle demonstration of the effect of deer herd reduction as a means to lower risk (Rand et al. 2004), as well as our involvement in a successful vaccine trial for Lyme disease, which recruited more than 200 Maine citizens (Steere et al. 1998). As more diseases were attributed to deer tick bites, we have contributed to the scientific understanding of the epidemiology and spectrum of these diseases. As cases of these diseases increased in Maine, we have broadened our clinical studies beyond Maine and collaborated with leading medical institutions in the Northeast to describe the variation in skin rashes associated with proven Lyme disease (Smith et al. 2002) , to demonstrate differences in presentation of Lyme arthritis between children and adults (Daikh et al. 2013) , to describe the clinical spectrum of Lyme carditis (in preparation), and to seek biomarkers of infection in Lyme meningitis (Angel et al 2012) . We have presented our research on Lyme disease, anaplasmosis, babesiosis, and deer tick virus (Powassan) encephalitis in national and international forums. Currently, we have organized a network of clinicians involving three Maine hospitals to examine the effectiveness of a novel means of diagnosis of early Lyme disease, with a grant award from the National Institutes of Health.

We applaud the support for Centers of Excellence in the study and prevention of tick borne diseases, and would suggest that a northern New England area of research focus would provide unique insights into the variations in ecologic contributors to deer tick colonization and survival and to regionally informed interventions to lower disease risk. Similarly, we envision development of a clinical trials network in Maine and other New England states that can assist in developing evidence based solutions to current questions related to diagnosis and treatment of these diseases. There are particular needs for additional trials incorporating special population groups such as the pediatric age group, the elderly, and immune-suppressed individuals. The incidence of these diseases in our state, the availability of a multi-disciplinary care and research teams, and the infrastructure already in place here make Maine a key site for continued development and implementation of science based preventive and treatment strategies.

We are happy to provide more detailed information on our work and commentary on this bill if requested.

Respectfully,

Robert Smith MD, MPH
Director Adult Infectious Diseases, MMC
PI, Vector-borne Disease Laboratory, Maine Medical Center Research Institute
Professor of Medicine, Tufts University School of Medicine

Carol A. McCarthy MD
Director, Pediatric Infectious Diseases, MMC
Associate Professor of Pediatrics, Tufts University School of Medicine

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Testimony of Paula A. Doucette

Dear respectable and honorable members of The United States Senate Committee on Aging,

I am so thankful to have the opportunity today to share my testimony with you and to encourage all Senators nationwide to support of the TICK Act Bill, a gravely needed bill not only for Mainers, but for all people of our country, the United States of America.

Three years ago I was forced to give up my beloved career as a Pediatric Nurse working with medically fragile children with special needs. Shortly after, I lost my ability to drive, followed by a drastic and serious sudden crash in my health resulting in crippling and even life-threatening symptoms ultimately leading to being bedridden for most of the following two years and requiring my Husband to care for me. The following year I was diagnosed with Lyme (and several coinfections), which due to the length of time between tick bite and diagnosis (over 15 years) had spread to my heart, lungs, and brain. I never had the bull's eye rash, and was told by medical professionals that I was ok where I did not get the rash.

The past 3 years have been a horrific hell, financially devastating, and extremely emotionally traumatic for my Husband, myself, and my children. We lost over half our monthly income when I lost the ability to work. Due to the neurological and physical symptoms I was unable to work, but also could not qualify for help due to grave wide spread misconceptions about Lyme. Our family quickly went though all of our emergency savings. Thankfully, after being treated awfully by medical professionals not educated properly about Lyme, I was connected to a Lyme Literate practitioner. It has taken 3 years to heal enough to be able to walk and drive again. I still am healing, and still unable to work outside the home due to effects of the disease. My family is still healing from the emotional trauma.

This summer my 11 year old daughter after having unrelenting fatigue, emotional symptoms, trouble with her memory to the point it affected her grades, and having signs of compromised immunity was diagnosed with Lyme that with test results showed she had for atleast 8-9 years. It is believed that she and my son, her twin brother, who is being tested soon, were infected congenitally from me before I knew I was infected. This is very scary for us considering the loss of my income, myself still being in treatment, the fact that the treatments that are healing are not covered by insurance, and emotionally my children are shaken after seeing their Mom be bedridden in crippling pain by the disease they now know they have.

I wish that our family could have been spared all we have suffered through these past few years. I pray that this short synopsis of our story touches your heart thinking of your family. I pray that you take action now and support the TICK Act to put into action steps now to stop the rapid and wide spread devastation of this horrific disease.

Thank you greatly for your time,

Sincerely,

Paula A. Doucette

Testimony of Tracey Allen, Scarborough Maine

I am a 64yo female, 90% disabled veteran, who was bitten by a tick in Oct 2015. I was healthy, physically active, living on my own, running a small farm and participating in veteran's activities before I was bitten by a deer tick in 2015. This is my story of malpractice and negligence by the VA in Maine.

On Fri Oct 16, 2015 at 9pm I found an embedded tick on my back surrounded by a bulls eye type rash. The rash had an approximately 1"
dark purple center surrounded by an approximately 4" diameter red rash.
As a veterinary technician and farmer I am familiar with ticks. I have never had a reaction to a tick bite like this before. It was a Deer tick not a dog tick.

On Sat Oct 17th I made an appointment at the Saco VA for Mon Oct 19 for my sprained ankle which was still sore and the tick bite.

On Mon Oct 19 I showed the tick to Dr Stawasz, my PCP at the Saco VA, and told her I was sure it was a deer tick. The rash around the center bite site was gone and she measured the inner inflamed area that was left. Dr Stawasz told me twice that "just because it's a deer tick doesn't mean it has Lyme disease". Since I don't take antibiotics unless it's really necessary, I agreed to wait on antibiotics to see if I had any other symptoms. Per the CDC's webpage in Oct 2015, antibiotics were to be started if any flu like symptoms appeared within 30 days. A Lyme Disease test was scheduled for Dec 7, 2015 (7+ weeks from the date of the bite).

A week later on 25 Oct 2015, I started with a fever that ranged from
99.8* to 100.5* and had a severe headache and other flu and meningitis like symptoms for 5 days. The fever broke and I was OK for two days and then the fever returned and was 101*-102+* for the next five days with increasingly severe symptoms. The fever broke again and I was slightly better for three weeks and then the symptoms came back with only a slight fever for another five days. My symptoms varied but always included severe headaches, joint and muscle pain, and severe fatigue.

On 14 Dec, after getting negative test results on the first Lyme test, I let Saco VA know that I was still having symptoms of joint pain, head ache, earaches and fever. They repeated the Lyme test a month later but never scheduled any other tests or a followup Drs visit.

The second Lyme test was negative on 7 Jan 2016 but no other followup was done. By this time I was well educated in the symptoms and treatments of Lyme and tick co-infections and had been self treating with herbs which were keeping the symptoms tolerable during flare-ups.
Between flare-ups, when I was basically bedridden for anywhere from 1-4 days, I was very weak and still sickly but at least could care for myself and do errands for short periods of time. I did not contact the VA again because it was obvious they had no intention of treating me and contacting them is extremely frustrating and a waste of time.

I was saving up money to go to an outside provider when my annual VA exam came due on 21 Apr 2016. I told Dr Stawasz that I was still sick and my other healthcare providers agreed that I likely had Lyme disease.
She asked me if anyone else had given me antibiotics! The VA is supposed to be providing my medical care since I'm 90% permanently disabled. She finally decided to send me to an Infectious Disease Dr at Togus VA, Rekha Goswami.

On 6 May 2016 I paid $50, out of pocket, to have the tick itself tested at the University of Mass for several tick-born diseases.

On 10 May 2016 I met with Dr Goswami at Togus VA. She informed me that I likely had fibromyalgia or chronic fatigue because it couldn't be Lyme with a negative Lyme test. Or maybe my symptoms were due to my low WBC count. (Dr Stawasz said the low WBC was normal for me.) She then did an "exam" which started with asking way too many questions about my mental health, inferring that it was a "Psycho-social" problem. After twenty minutes of trying to convince me she knew a lot about Lyme disease (all straight off of the CDC website) and my telling her that current research said otherwise, she finally decided to order more tests for other tick-born diseases and repeated the Lyme tests (#3) but did not give me any antibiotics.

On 10 May 2016, when I got home from the VA, I got an email from U Mass about the tick they tested which indicated the tick was positive for Anaplasma. After notifying Dr Goswami she put me on Doxycycline 100mg 2x day for 2 weeks. The substitute Dr for Dr Goswami (Dr Neal) called me four days after that to give me the test results and told me I likely didn't have an "active" case of Anaplasmosis because my blood tests were normal. My blood tests weren't normal because my WBC is low enough that Dr Goswami said to keep an eye on it and my other tests didn't take into consideration my extensive use of herbs.

I immediately contacted a local Dr with years of experience treating Lyme disease because I knew that the prescription for Doxycycline was inadequate. Dr Heidi Chester of Integrative Health Center of Maine wrote me a prescription to adjust the dosage and length of treatment based on my health history which indicated I might have had Lyme disease since 2008, as well as Anaplasmosis. Because I had to pay for the Doxycycline out of pocket (and the price was ridiculously high), I only filled it for two weeks while doubling up the VA prescription and taking it all the first week. I never took the forth week of Doxy because of severe photosensitivity.

I inquired of the VA for drawing blood to be sent to Igenex in CA for a different Lyme test. I was informed that the VA did not draw blood for third party tests so I paid out of pocket for DR Chester to do it. As a result of that inquiry I was scheduled by Dr Goswami for another round of blood tests including another Lyme test. (#4) It came back negative for the fourth time. Our tax payer money at work.

I never heard from the VA to follow up on the results of taking the Doxycycline. I sent a message to Dr Stawasz on 7 July 2016 saying that I had had another several days of "flare" of symptoms. I never got an answer.

I sent a message to Dr Stawasz attaching the Igenex test results when it came back positive for Lyme. Never got a response back. I went to see Dr David Thornton in VA Infectious Disease in Boston on 6/30/17. He said I had symptoms of ME/CFS (chronic fatigue) but didn't think I had "active"
Lyme because of the negative Lyme tests.

It's now Sept 2019 and since May of 2016 I have received no treatment from the VA, except for acupuncture twice a month for pain. That doesn't even come close to addressing my pain issues so I use CBD and have a medical marijuana card. I have cardiac and neurological symptoms and am now totally disabled by pain and fatigue. I have many, many symptoms and am getting progressively worse. I am still paying to see Dr Chester, cash out of pocket, a couple times a year and getting diagnostic testing done that the VA refuses to do as I can afford it. Dr Chester diagnosed me with ME/CFS, Fibromyalgia, Orthostatic Intolerance and Post Exertional Malaise in 2018. The VA still denies there is anything wrong with me. I am also paying cash for prescriptions that the VA won't pay for, all while living off of VA disability. I signed up for Social Security years early to afford to pay for the outside medical care that is keeping me alive, taking a big hit in the long term financially. I am likely going to be forced to move out of my house because I live alone and can't physically mow, snow blow, shovel and do basic maintenance any longer. I can't afford to buy or rent anything in Greater Portland which is where my only family is in State.

I am recording this in the hope that the Senate will:
1. Take steps to address the epidemic of tick borne diseases (TBD) that are devastating this country by requiring the CDC to be more clear about diagnosis and treatment, since the VA is using the CDC as guidelines.

2. Require the VA to use ILADS guidelines, not just the CDC in diagnostics and treatment.

3. Stop using IDSA guidelines because the IDSA is a private organization with commercial conflicts of interest.

4. Require the VA to track and report all suspected and confirmed cases of TBD, nationally with diagnosis, treatment, and outcome.

5. Require the VA to track and report all cases of ME/CFS, fibromyalgia, multiple sclerosis, Parkinson's and mental health issues that respond to treatment with antibiotics, indicating a TBD was the cause of the disease.

6. Increase oversight of the VA by monitoring results from the White House Hotline and taking action swiftly to clean up the hiring of "bad"
Drs and replace corrupt and/ or ineffective administrators.

7. Pass laws to force insurance companies to cover healthcare for TBD

8. Pass laws to protect Drs who treat Lyme patients from persecution by insurance companies and State medical boards.

9. Enhance the Mission Act to allow veterans to see their own MD or ND in the community for primary care without having to jump through VA "hoops".

Thank you for adding my statements to the official record. I hope it will help changes to be made!

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