

**New York Senate Task Force on Lyme and Tick Borne Disease and
The Senate Standing Committee on Health**

***Senator Sue Serino, Chair
Senate Task Force on Lyme and Tick-Borne Diseases***

***Senator Kemp Hannon, Chair
Senate Standing Committee on Health***

Senator Serino and Senator Hannon, first of all thank you very much for the invitation to offer these thoughts for the record of your very important hearing.

My name is James P. Donick. I live in LaGrange/Pleasant Valley, which is in Senator Serino's district. I am a feature writer for the **Northern Dutchess News** as well a contributor to a number of publications on topics ranging from Theatre and Hudson Valley life to model aviation, sports car racing, and automotive history. As a result of these activities I am fortunate to meet interesting people all over the world and to be able to relate their stories.

I'm also a sufferer with what I am told is the neurologic variety of Chronic Lyme disease and have been being treated with antibiotics for roughly twenty years. On that I'll offer more anon.

The first point I would like to offer you is the story of the daughter of a friend of mine. He is associated with the racing circuit of La Sarthe, in France, the site of the famous annual 24 Hours of LeMans. We were together there in the spring and he related the story of his daughter's experience with Lyme.

She is just over thirty years old and is a teacher. A year ago she visited New York on vacation and had a marvelous and memorable time. This, obviously, is the experience we wish for all of our foreign visitors. Unfortunately for this young woman, though, she took home an unexpected souvenir of her sojourn. She had contracted what was diagnosed as Lyme Disease. Her's was a particularly nasty case. Her symptoms were severe enough to make working impossible. She lost her apartment and moved back in with her parents. For a long time she wasn't even able to be up and about for a whole day but needed to retreat to bed part of most days. The antibiotic regimen also took its not uncommon toll on her digestive system, further weakening her.

It seems that Germany is currently enjoying a reputation as the leading source of Lyme treatment in Europe. In the spring of this year her father was having to contemplate selling one of his cars to raise the cash to try taking her to Germany for treatment. France having nationalized medicine means that sending the young lady to Germany for treatment would have cost the family a great deal.

I spoke with my friend in France a few weeks ago and can report that his daughter is currently showing some improvement and has not yet had to seek additional treatment in Germany. The jury, however, is still out as she is still unable to work.

I am told that Lyme is now becoming well known in Europe and I can guess that it is also becoming too well known around the world. My friend's family are comfortably well off, though not rich. Still, they travel for their vacations and they have many friends within their social strata who do the same. New York currently enjoys a booming Tourist industry. Here in

the Hudson Valley I will occasionally find myself speaking French to visitors when out for my all-but-daily stroll on the Walkway Over the Hudson. From time to time I even get to practice my Russian. I can attest to you that the threat of contracting Lyme Disease is now becoming a topic of conversation amongst my French friends and is becoming a negative factor in their holiday planning. This is an economic issue for the state and one that will only grow unless we manage to eliminate or to at least mitigate the effects of Lyme Disease and the apparently rising number of other debilitating tick-borne illnesses.

My second point, Senators, is more personal. I've got Chronic Lyme and it lives in my spinal fluid and - they tell me - in the fluid around my brain. That's pretty frightening.

I'll not bore you with how all of this developed inside me except to note that twenty years or so ago the disease was not understood even close to how well it is understood today. I was crossing the ocean three and four times a month back then and just chalked my problems up to chronic jet lag and fatigue. I was wrong and waited too long for diagnosis and treatment.

I've been on a maintenance dose of antibiotics now for over twenty years. The disease flares up from time to time and we have to add additional antibiotic for a period to bring it back under control. Sometimes the biggest symptom is a difficulty in finding words halfway through a sentence. For a writer, this is more than worrisome.

There appear to be all sorts of approaches or even fads for treating Chronic Lyme from dietary changes like avoiding Gluten or alcohol to pharmacological approaches using various mixtures of what amounts to antibiotic cocktails, vitamins, antidepressants and, who-knows-what-else. For instance I was recently introduced to a study - yes a real study - at the University of New Haven, which is near to ground zero for Lyme Disease, that found there may be value in a natural sweetener product called Stevia, for Chronic Lyme. I'm not qualified to offer judgment on the treatment but am impressed with the legitimacy of the source of the study. This isn't the sort of study that a major drug manufacturer would have an interest in funding. Thus, government funding is absolutely necessary. There must be other interesting trails to follow as well.

In truth, I can only beg you to make the necessary resources available to researchers in a wide variety of clinical approaches to put this scourge to bed. I rather expect it to kill me one of these days but certainly not this week.

Thank you again for your kindness in welcoming my testimony and for your graciousness in reading it.

Please remember that those of us suffering from Chronic Lyme have very little hope of cure unless new research proves fruitful.

It is important also to acknowledge that tick-borne illnesses are a threat to New York on a larger economic scale. The threat of Lyme may soon begin to become a serious detriment to foreign tourists considering a vacation in New York. The loss of those visitors would be a potential economic threat to the state as well as a sadly lost opportunity to introduce people from around the world to the beauties of New York State and to introduce New Yorkers to the perspectives those visitors would offer.

Don't let this happen.

Thank you.



State University of New York
College of Environmental Science and Forestry
Department of Environmental and Forest Biology

Dear Senators Serino and Hannon,

I would like to thank the New York State Senate and the Task Force On Tick and Tick Borne-Diseases and Committee on Health for organizing this hearing and giving me the opportunity to provide my written testimony.

Formally described in the early 1980's, Lyme disease has become an ever increasing global threat to human health. Shortly after the discovery of *Borrelia burgdorferi*, a spiral-shaped bacterium or "spirochete", similar organisms were identified in ticks and patients in both Europe and Asia. Today there exists ~21 bacteria in the Lyme disease complex. Yet, for the majority of these organisms their ability to infect and cause disease in humans remains unknown. For example, for the past 30 years only one species of bacteria (*Borrelia burgdorferi*) was considered to be responsible for the majority of human Lyme disease cases in North America, despite 10 known spirochetes found in ticks and small mammals across the US. Only recently, through extensive genetic testing of patient samples (~100,000), have researchers at the Centers for Disease Control (CDC) and the Mayo Clinic categorized an additional *Borrelia* spirochete as a human disease causing agent (in 13 patients).

Do the other eight species of *Borrelia* spirochetes cause human illness?

We really do not know.

My lab as well as few others have found that these organisms do cause disease in common laboratory mouse models used to study Lyme arthritis and carditis (inflammation of heart tissues), but we currently have a very infantile understanding of these organisms. However, because of their relative similarities and minor differences, continued study of these organisms may give us an unprecedented insight into the spirochete most commonly implicated in human Lyme disease as well as an answer the above question.

Why study Lyme disease? In 2015 there were ~38,000 cases of Lyme disease reported to the CDC. However, recent studies by the CDC find that the true case number is likely 10 times higher (380,000 cases annually). Given these findings, if one looks back on the number of reported cases of Lyme disease from 2000-2015 and adjust for underestimation we arrive at a staggering 4,448,690 cases. At an estimated health care cost of \$3000/patient, Lyme disease costs the US health care system between \$712 million to \$1.3 billion annually. If we then break these numbers down to cases just in New York State we can estimate that ~746,600 cases of Lyme disease have occurred in New York in that 15 year period. That is almost 50,000 cases annually, meaning ~2.5% of New Yorkers will get Lyme disease each year, resulting in health



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care costs of ~\$150 million annually. When we consider that ~15% of patients with Lyme disease will have symptoms even after antibiotic treatment (regarded as Post Treatment Lyme Disease Syndrome), then each year ~7,500 (15% of 50,000) New Yorkers will suffer from long term effects from the disease resulting in increased medical cost and loss of productivity (estimated ~\$4,000/patient). In addition to the obvious medical costs associated with disease, there exists an additional economic concern to New York State. This is the loss of recreational tourism due to fear of contracting Lyme disease, which in the Northeast United States is estimated at \$2.8-5 billion per year.

Southeastern New York has been an epicenter for Lyme disease, while counties to the north and west have only recently seen increases in this disease and its vector tick. This places New York State in a unique position to take the lead on the understanding, treatment and prevention of tick-borne diseases like Lyme. State supported programs such as SUNY 2020 (funding for the construction of a state of the art vector-borne disease laboratory at Upstate Medical University), SUNY Empire Innovation Program and various state agencies like the New York State Departments of Health and Environmental Conservation have provided foundational funding and resources towards this goal. Taking the lead on this research should be scientist and clinicians at the 64 SUNY campuses spread across the state, supported by the state as well as federal government. Almost every day it seems we turn on the TV and mainstream media is reporting on another tick-borne disease we should be concerned about. Viruses such as Bourbon, Heartland and Powassan; bacterial diseases like Rocky Mountain Spotted Fever and Anaplasmosis; a malarial-like organism (*babesia*) that may have entered the national supply of banked blood and even an allergy to red meat possibly triggered by an over-reactive immune response to tick saliva all have garnered national attention in recent years. Yet like the “other 8” North American Lyme disease spirochetes, we still know very little about the majority of these disease causing agents. **Considering the scope of the problem, federal dollar supporting work on tick-borne diseases are petty at best.** Lyme disease likely infects ~380,000 Americans each year; however the National Institutes of Health (NIH), the largest federal granting agency, has only ~\$29 million dollars budgeted for research on this disease in 2018 and only \$22 million in 2019. That means \$76 per patient. Compare that with a disease like Small Pox where the last two cases of human small pox occurred in 1978 in England; and although a potential bioterrorism agent, it is a vaccine preventable disease. Still, NIH funding for Small Pox research sits at \$51 million in 2018 and \$38 million in 2019.

I have studied Lyme and other tick-borne diseases for the past 10 years. Prior to that I practiced as a paramedic. I know the face of human disease and suffering. As of August 25th 2017 I am the father of a beautiful baby boy, and although I have yet to contract Lyme disease myself I will worry about my son’s health as he grows up and plays outdoors because of what I know about



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this organism as well as other tick-borne disease agents. I know that I do not stand alone with this concern. I am sure you have heard some very moving testimonies today and I hope this hearing fuels more efforts to support the study of Lyme as well as other tick-borne diseases, which are becoming ever prevalent in society.

Where should research priorities lie? In my professional opinion the most critical research needs are as follows:

- 1) Basic research into the role of other spirochetes in human illness
- 2) Basic research into new and emerging tick-borne disease agents
- 3) Research into better tick-borne disease diagnostics
- 4) Research into novel methods to prevent tick-borne disease transmission

Best Regards,

A handwritten signature in black ink, appearing to read 'Brian F. Leydet Jr.', written in a cursive style.

Brian F. Leydet Jr, MPH, PhD
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Columbia County Department of Health

John J. Mabb, MA
Public Health Director

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August 29, 2017

Dear Senators:

Thank you for the opportunity for the Communicable Disease staff of the Columbia County Department of Health to share our input regarding the Tick-borne Learning Collaborative and arthropod diseases in New York State in general with the Senate Task Force on Lyme and Tick Borne Diseases.

As a Registered Nurse of the Communicable Disease team of Columbia County, a good portion of my work involves the surveillance, investigation and reporting of arthropod diseases in Columbia County, as well as continued education on the prevention of these diseases to both our community and our providers.

I have attended several of the NYS Tick-borne Collaboratives and always feel that I take home a plethora of knowledge that we apply to our daily work. First and foremost, we network with our intrastate counterparts and regional program people to exchange new ideas and best practices to strengthen our knowledge base. We in turn share the information learned with our other county disciplines such as Environmental Health and Public Health Education. This collaborative learning is a forum for sharing of information, resources and ideas. The information that is shared at these meetings is critical in that, as the arthropod disease trends change, we need to stay abreast of the most current information and changes in the laboratory testing and interpretation.

The diversity of the information and expertise that is shared at these Collaboratives is impressive: keynote speakers, researchers, physicians, our regional epidemiologists - all experts in their fields, all sharing relevant and varied knowledge. The knowledge obtained at these events include the following: information on changes in testing procedures and case definitions; updates on the status of possible new Lyme vaccine; the Tick-borne Education Campaign targeting 2nd-5th graders to start the education early; the "Ticks on the Move" video that reached thousands people throughout NYS via sharing on local health Department websites; community measures being trialed like the 4-Poster feeding boxes to self treat deer to kill the ticks but not hurt the deer population itself; permethrin-treated feedboxes that target the mice population; yard-based interventions; education on emerging tickborne diseases such as Miyomati and Powassan; handling press inquiries; the controversial "Post-Arthropod Syndrome"; sharing of case histories by other counties to examine best practices across the state; and much more.

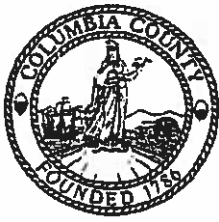
I hope that these learning conferences can continue as they provide a life-line to the local Health Departments and enable us to better do our jobs, with our partners, for our community.

Sincerely,

Pamela A. Ferber, RN

Pamela Ferber, RN

Communicable Disease



Columbia County Department of Health

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August 25, 2017

Senator Serino & Senator Hannon:

I am an RN who is employed at Columbia County Health Department in Hudson, New York. I work in the Communicable Disease Department and am primarily responsible for Arthropod Surveillance and Investigation in this highly endemic area.

I have attended the Tick-borne Learning Collaborative for the past two years and have found it to be informative, collegial, and relevant to my daily work. I find it is beneficial to establish relationships among colleagues in other parts of the State to brainstorm ideas regarding prevention and education of tick-borne illnesses, to understand current Arthropod trends and ever evolving Arthropod illnesses, and to discuss solutions to these problems. Arthropod numbers in our County have been increasing, particularly regarding Babesiosis and Ehrlichiosis cases.

While I think that Arthropod disease prevention information has been largely disseminated, I think there are still individuals who do not take these illnesses seriously and do not use prevention measures as they should. I also feel there is a large environmental component involved in arresting the spread of Arthropod illnesses.

I do hope these Arthropod conferences continue as these illnesses are not going away and unfortunately are increasing and evolving.

Respectfully yours,

A handwritten signature in black ink, appearing to read "Cheryl Ronsani RN".

Cheryl Ronsani, RN
Communicable Disease

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August 28, 2017

Dear Senator Kemp Hannon and Senator Sue Serino,

I thank you for the invitation to participate in your public hearing on Lyme and Tick-Borne diseases. Unfortunately, I am unable to attend the hearing in person, and so I am instead providing written testimony on my experience with tick-borne diseases, and more specifically, with allergy to galactose- α -1,3-galactose, or alpha-gal. I am a board-certified allergist/immunologist currently practicing in Southampton, NY, as part of ENT and Allergy Associates, LLP. I am a medical advisor for the Regional Tick-Borne Disease Resource Center at Stony Brook Southampton Hospital. I am a member of the Suffolk County Board of Health, appointed by the Suffolk County Legislature in 2017. I was the first physician to identify the presence of alpha-gal allergy on Long Island, and since 2011, I have diagnosed over 400 patients with this allergy.

In February 2009, researchers at the University of Virginia identified a novel allergy to mammalian meat. Patients with this allergy developed allergic reactions 3-6 hours after ingestion of mammalian meat. The responsible allergen for this reaction has been identified as galactose- α -1,3-galactose (α -gal), which is a blood group carbohydrate present in all non-primate mammals. Patients with this allergy develop IgE antibody that recognizes and binds to the α -gal sugar, subsequently triggering an allergic reaction. This allergy differs from most other food allergies in several important ways. First, the allergy develops in response to a carbohydrate allergen, whereas the vast majority of other food allergies occur in response to a protein allergen. Second, the reaction is delayed by 3-6 hours, whereas most IgE-mediated food allergies occur within minutes of food ingestion. Third, patients who develop this allergy have previously been able to tolerate meat most of their life without issue, while most other food allergies present early in life. This unexpected finding raised a question for researchers: What is the inciting trigger for the development of this allergy?

As more and more patients were identified with α -gal allergy, it became clear that there was a regional distribution of cases, centralized in the Southeastern United States. Researchers noted that the distribution of α -gal cases followed a geographical pattern similar to that seen for certain tick-borne illnesses. Additionally, a number of patients reported that they developed the allergy after experiencing multiple tick bites. Subsequent research looking at the relationship between tick

bites and development of α -gal allergy was able to demonstrate a causative link between bites from the lone star tick (*Amblyomma americanum*), and the development of α -gal allergy.

Patients with α -gal allergy will usually describe a history of a tick bite, and more commonly will report multiple tick bites, or "chigger" (larval tick) bites. In my experience, α -gal allergy is more commonly seen in patients with jobs or hobbies that increase their risk of tick exposure. Patients with the allergy often spend time hiking or mountain biking, hunting, landscaping, or gardening.

Patients with α -gal allergy can present with symptoms ranging from generalized hives, swelling, and itching, to anaphylaxis, which is a multi-system allergic reaction that, in severe cases, can lead to death, though no α -gal related fatalities have been reported to date. Due to the fact that reactions to α -gal occur 3-6 hours after meat ingestion, the classic patient with α -gal allergy gives a history of awakening in the middle of the night with severe itching, redness, and hives over their entire body. Patients with more severe episodes may also describe abdominal cramping, vomiting, diarrhea, wheezing, shortness of breath, or even loss of consciousness. Patients with the allergy often require treatment with injectable epinephrine, and many require acute care in the emergency room. The patients invariably give a history of ingesting mammalian meat such as beef, pork, or lamb prior to the reaction. Reactions do not necessarily occur each time a patient ingests meat. Reactions are more likely to occur when a large quantity of meat is consumed, and meats that are higher in fat are more likely to trigger a reaction. Dairy products do contain a small amount of α -gal, and patients with this allergy will often demonstrate IgE antibody for milk, but this is rarely of any clinical significance. Gelatin, which is frequently derived from beef or pork, does contain α -gal, and there are cases of patients experiencing clinical symptoms after gelatin ingestion.

The Lone Star tick territory is expanding, according to data from the CDC (see below). Scott Campbell, PhD, the Chief of the Arthropod-Borne Disease Laboratory for the Suffolk County Department of Health, predicts that the Lone Star tick territory will continue to expand in Long Island and New York State as a whole, as the deer territory continues to expand. Lone Star ticks depend on deer for survival. Alpha-gal allergy has already reached epidemic proportions on the north and south forks of Suffolk County, Long Island, but I have also diagnosed cases of this allergy further west in Suffolk County, in towns such as East Islip and Port Jefferson, as the deer increase their territory. I believe there is good reason to be concerned that this allergy will become more of a state-wide epidemic.

Senator Kemp Hannon and Senator Sue Serino

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https://www.cdc.gov/ticks/geographic_distribution.html

Funding research on α -gal allergy has also been a challenge. As this allergy was largely believed to be limited to the Southeast United States until about 7 years ago, most of the ongoing clinical and laboratory research on this allergy has been taking place at University of Virginia and University of North Carolina, in the hands of Drs. Thomas Platts-Mills (UVA) and Scott P. Commins (UNC), and they hope to soon add me as a site for their clinical research/data collection. Dr. Commins has had difficulty procuring the funding necessary to perform important research to help better understand the immunology and pathophysiology of this allergy. Additionally, while I have personally diagnosed over 400 patients with this allergy over the past 7 years, since it is not an "infectious disease," so to speak, it is not reportable to the CDC. Funding is needed so that we can better track and characterize the geographical distribution and incidence rate of this potentially severe food allergy.

While my area of expertise related to ticks is largely limited to α -gal allergy, as a member of the Medical Advisory Board for the Regional Tick-Borne Disease Resource Center at Stony Brook Southampton Hospital, I can also attest to the fact that Suffolk County, and particularly the east end of Long Island, is dealing with tick-borne diseases in epidemic proportions. As I am sure you are already aware, Newsday recently reported Long Island statistics on tick-borne illnesses in Nassau and Suffolk Counties over the past 3 years (see below).

LONG ISLAND NUMBERS ON TICK-BORNE ILLNESSES (As reported in Newsday 8/17/17)

Source: Suffolk County Department of Health Services

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Suffolk County

Babesiosis

2014 - 204

2015 - 215

2016 – 156

Ehrlichiosis/Anaplasmosis

2014 - 119

2015 - 101

2016 – 123

Lyme disease

2014 - 654

2015 - 669

2016 – 644

Rocky Mountain spotted fever

2014 - 8

2015 - 8

2016 – 13

Powassan virus

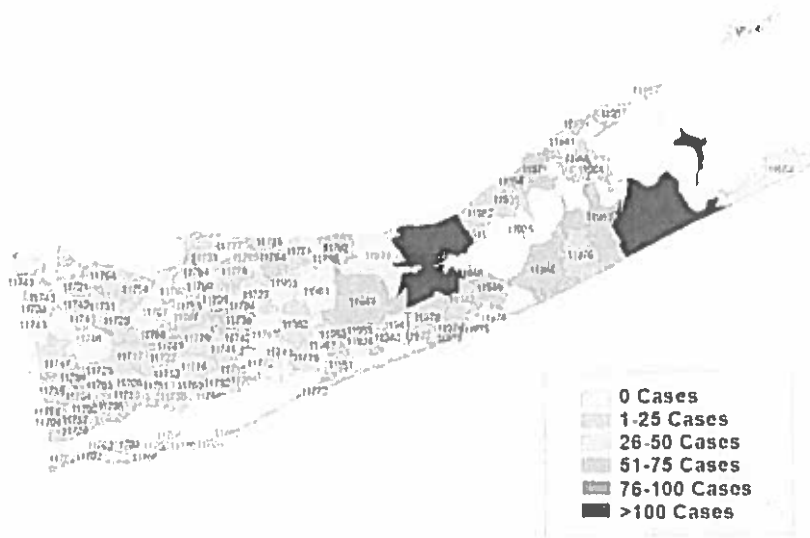
2014 - 0

2015 - 0

2016 – 0

In response to these staggering numbers, which are by far noted with greatest density on the eastern end of Suffolk County (see case map for Lyme disease below), the Regional Tick-Borne Disease Resource Center at Stony Brook Southampton Hospital was created in 2014.

Suffolk County Lyme Disease Cases 2010-2014



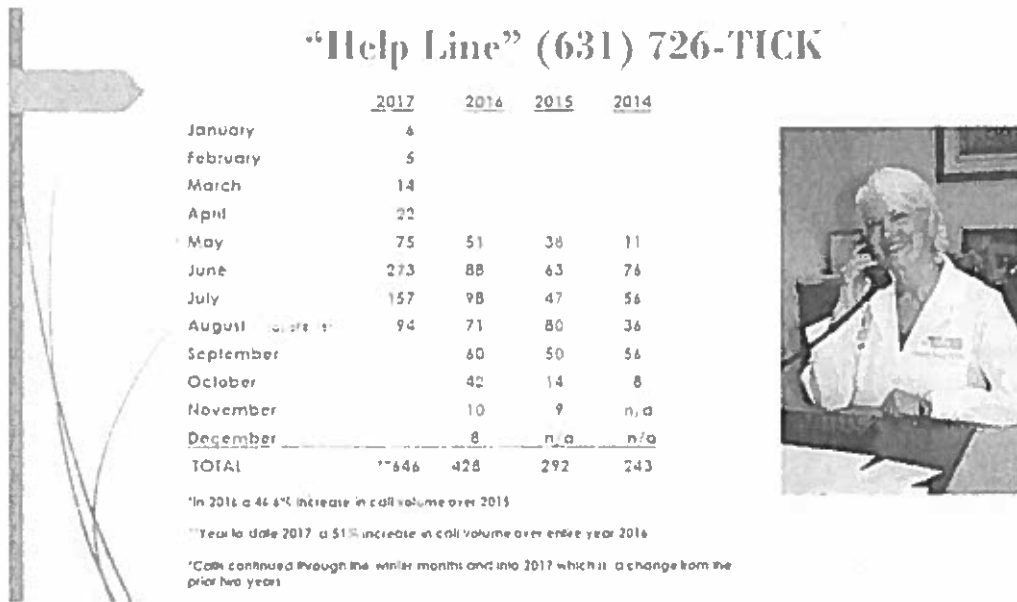
Suffolk County Lyme Disease Cases 2010-2014. Data obtained from NYSDOH CDESS

The Regional Tick-Borne Disease Resource Center at Stony Brook Southampton Hospital was developed with a mission to educate the public, promote collaboration within the medical community, and facilitates access to diagnosis and treatment of tick-borne diseases. We are a resource serving both the public and the medical community, providing education, guidance and access to treatment for Lyme and other tick-borne diseases. We maintain a dedicated phone “help” line for advice, as well as a specific area on Stony Brook Southampton Hospital’s website, containing comprehensive information about the complex set of diseases which may be potentially transmitted by the bite of an infected tick. We raise public awareness in the community by holding periodic educational symposia in a variety of venues which are designed to educate and inform. We promote collaboration among Eastern Long Island medical professionals to strengthen their ability to combat the epidemic of tick-borne diseases.

Our medical advisory panel is made up of physicians, nurses, nurse practitioners, physician assistants, psychologists, and hospital administrators. The panel is made up of physicians and other healthcare providers from a variety of different disciplines, including family practice, internal medicine, emergency medicine, pediatrics, cardiology, neurology, infectious disease, allergy/immunology, psychology, and infection control. In addition, we have a scientific advisory panel, consisting of the following experts:

- | | |
|------------------------|--|
| Benjamin J. Luft, MD | SUNY Stony Brook School of Medicine |
| Patricia K. Coyle, MD | SUNY Stony Brook School of Medicine |
| Steven E. Schutzer, MD | Rutgers-New Jersey School of Medicine |
| Scott R. Campbell, PhD | Suffolk County Department of Health Services |

The slide inserted below shows the number of calls received by our free tick “hotline, from the time of our center’s inception in 2014 to the present. Our hotline is manned by Rebecca Young, RN, BSN. We are on pace to double our call volume from 2016. Rebecca reports an average of 15+ call per day for the 2017 tick season.



Since 2014, the center has hosted 12 professional medical symposia for clinicians to educate them on various aspects of tick-borne diseases and testing methods, and on September 28, 2017, we will hold an All-Day Symposium Sponsored by the Resource Center at Stony Brook Southampton Campus, entitled “Understanding the Complexities of Tick-Borne Disease.” This symposium will be offered free of charge for medical professionals, and 6 CME credits will be available to participants.

In addition, since its inception, the Resource Center has hosted a number of free community educational events, including 31 educational programs for adults, and 20 educational programs for children to date, with more events planned for the fall (schools, libraries, camps). We will continue to fulfill requests for educational lectures this year. Not just on the East End of Long Island. We have gone as far west as Huntington, Shoreham, Centereach, and Brentwood.

The center also participate in a number of research partnerships, as noted:

Rutgers – New Jersey School of Medicine Steven E. Schutzer, MD, Anna-Marie Wellins, DNP

- NIH-funded study for rapid-result diagnostic test for Lyme

Stony Brook School of Medicine Benjamin J. Luft, MD, Luis A. Marcos, MD, MPH

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- Incidence of Lyme disease in the Hispanic Population on Eastern Long Island
- Vaccine for Lyme disease
- Neuroimaging in patients with persistent Lyme disease

The Hospital does not cover the costs of operating the Resource Center. We are dependent on Grants and charitable contributions to continue operating. It takes between \$75,000 and \$100,000 per year to cover operating expenses. As we continue to grow so will our costs.

In summary, both α -gal allergy and tick-borne diseases are reaching epidemic proportions on the eastern end of Suffolk County, and the incidence of these diseases/allergies are on the rise. All signs indicate that the territory of the Lone Star tick is expanding, and I do anticipate that α -gal allergy will become an increasingly common condition in New York State. The medical and scientific advisors for the Regional Tick-Borne Disease Resource Center at Stony Brook Southampton Hospital are doing everything we can to educate and provide resources for clinicians and patients alike, and are providing a database of patients to forward research into α -gal allergy as well as other tick-borne diseases. I commend you for holding a hearing on this incredibly important public health issue. I ask you to use your legislative power to do everything you can to help support us in this fight.

Please do not hesitate to contact me if you have any further questions or concerns.

Sincerely,

A handwritten signature in black ink, appearing to read 'Erin E. McGintee, MD'. The signature is stylized and cursive, with the initials 'EM' being particularly prominent.

Erin E. McGintee, MD
ENT and Allergy Associates, LLP
Suffolk County Board of Health



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August 29, 2017

The State Senate
State of New York

Dear Senator Sue Serino and Senator Kemp Hannon,

Thank you for this opportunity to provide input for your public hearing today. I apologize that I am unable to attend in person for this important event. Please accept my written testament for your discussion.

Saratoga County Public Health has witnessed a marked increase in the number of tick borne cases this year with an early start to the warm season. The prevalence of tick borne diseases is steadily climbing in Saratoga County. In order of frequency Lyme disease remains to be the highest reported cases; the frequency rates from higher to lower for other diseases: Ehrlichiosis/Anaplasma Phagocytophilum, Babesiosis, Ehrlichiosis/Ehrlichia Chaffeensis & Ehrlichiosis/Anaplasmosis undetermined, and Powassan Virus neuroinvasive and non-neuroinvasive cases. Lyme has been the most prevalently reported and we feel the numbers of other diseases are underreported.

Prevention measures have been stressed and educational outreach has been conducted through a variety of avenues. Saratoga Public Health has promoted the recommended prevention techniques from the DOH and CDC to individuals, group presentations to schools, senior citizen sites, health fairs and interested parties. We have handed out hundreds of tick kits with instruction on how to properly remove ticks. Educational pamphlets, brochures, website and Facebook media includes advice on prevention, tick removal, when to seek appropriate medical care for proper testing and treatment.

We recognize the most important aspect lies in protection from these diseases and each individual should protect themselves and their loved ones by preventing direct contact with these ticks. Recommendations given stress the practice to use regular/daily preventive measures when performing and experiencing outdoor activities; i.e., walking in the woods, hiking, hunting, gardening, yard work. Those who engage in those types of activities are most vulnerable; pet owners have noticed a rise in the number of ticks that are brought inside by their pets which increases the potential risk of exposure for humans.

CATHI DUNCAN, RN BSN
DIRECTOR OF PUBLIC HEALTH
EARLY INTERVENTION OFFICIAL

ERIN MURRAY, SPHN
PREVENTION

MICHELLE WOOD
FISCAL MANAGER

CATHY MEDICK, RN BSN
DIRECTOR OF PUBLIC HEALTH

LORI PITCHERALLE, SPHN
QUALITY ASSURANCE/PREVENTION

KERRY WHITE
EI PROGRAM MANAGER

BRANDT GREINER
EMERGENCY PREPAREDNESS COORDINATOR

Our mission: To assess, improve and monitor the health status of our community.

Recognizing the rising incidence of tick borne diseases we see the need for more funding to support the ongoing activities of education and outreach to our community members.

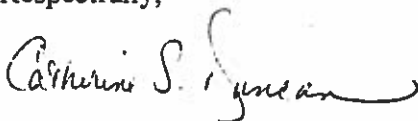
- Increase community awareness through public television, radio and other avenues to reach youth, adults and elderly age groups
- Types of protective measures that can be safely administered to everyone (children and pets); also a need to be affordable i.e., Deet and permethrin sprays
- Tick removal practices – monitor for ticks on a daily basis, and remove ticks promptly. Every household medicine cabinet should contain a tick removal kit
- Educate the public to seek medical intervention early by recognizing signs and symptoms of disease
- Primary care education on proper testing, and adequate treatment for all disease types

There should be further funding available to study these diseases and research on the following:

- Improvements in laboratory testing and reporting
- Research and development for vaccines
- Improved epidemiological collection of ticks and testing to properly inform the public of catchment areas
- Research in methods to reduce the number of ticks, implementation of methods as deemed appropriate and effective
- Further studies to develop medical measures that assure improved outcomes of debilitating symptoms

Thank you for your attention to this important health matter. I look forward to hearing about any outcomes and developments that may come from your hearing.

Respectfully,



Catherine S. Duncan, BSN, RN
Director of Public Health

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Our mission: To assess, improve and monitor the health status of our community.

Fw: Lyme hearing Susan Serino to: Kara Cumoletti 09/06/2017 11:24 AM This message is digitally signed.
 From: Susan Serino/senate
 To: Kara Cumoletti/senate@senate
 History: This message has been replied to.

NEW YORK Senator Sue Serino
STATE 41st District
SENATE 812 LEGISLATIVE OFFICE BUILDING
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-----Forwarded by Susan Serino/senate on 09/06/2017 11:23AM -----

To: Serino@nysenate.gov
 From: Kaethe Mitchell <kaethemitchell@gmail.com>
 Date: 08/31/2017 08:03AM
 Subject: Lyme hearing

Dear Sen. Serino,

Thank you for your work on the hearing on Lyme disease recently. I am in Sen. Akshar's district, but I wanted to reach out to you in order to thank you for being an advocate for us for so long.

I have two kids with chronic Lyme and one recently took her own life at age 19. Keara was never able to recover to a point where she wasn't in extreme pain every moment. Her functioning was minimal. She gave up after being ill most of her life. She had PTSD on top of everything. Both were treated by Dr. Steve Bock, who testified at the hearing. He never gave up on Keara, but she got to the point where she did not want to continue with treatments and she gave up.

Both our kids were misdiagnosed for years and the two-tiered testing is partially to blame. Neither case was reportable to NYSDOH due to the strict two-tier policy. One had a negative ELISA, but tested positive through Igenex years later. She is unreportable due to the negative ELISA. The other child never had the ELISA done, but had a positive Igenex. So she was unreportable since she never had the ELISA. It is ludicrous.

Our family is devastated, but at least we could afford to pay our of pocket for the lengthy treatments. Our other daughter is in remission but she has to be careful. She has relapsed twice and was rebitten and infected again last fall. She went to the urgent care near her college and they gave her only 10 days of doxycycline. We had to call Dr. Bock, who communicated with the urgent care provider to prescribe additional doxycycline. If we didn't have Dr. Bock, she would have been undertreated, like so many people.

The IDSA physician who testified, Dr. Sunil Sood, hopefully realizes after the hearing that there would be no issue if his IDSA guidelines were working. They are not.

This is just a tiny bit of our story. I hope you and Sen. Hannon continue to fight for us New Yorkers. Thank you.

Kaethe Mitchell
 Binghamton

My experience with Lyme in NY

Dear Senator Serino,

As a New Yorker who has been suffering with tick borne diseases for several years, I can't possibly thank you enough for all of your hard work trying to combat the tick-borne-disease problem in New York State. I sincerely wish I could attend the hearing on Tuesday, and join those with Lyme in calling for much needed change; However, my health keeps me from doing so at this time, and I will be unable to attend.

Instead, I am emailing my story to you in the hopes that something good can come from the great suffering I have experience the last 5 years, and that something I share may help the committee combat these illnesses more effectively.

I am 41 year old mom of 3 who has lived in New York my entire life. In 2010, I moved 10 minutes from where I had spent most of my life in Ulster County to a beautiful home in the foothills of Minnewaska State Park, where I had always wanted to live and raise my children. My entire life I had spent a lot of time outdoors and had taught my children to do the same. We were aware of the dangers of ticks and had always been careful to follow the advice of vigilantly checking for them whenever we were in the woods. Our vigilance kept us safe and free of tick borne disease until we moved here. Little did we know our lovely new home in the woods was in fact a perfect setting for massive numbers of ticks, and that all of the prevention measures we had ever heard of would not be able to save us.

We always checked ourselves for ticks after working or playing in the yard, walking in the woods, or spending time outdoors. Our pets wore preventative medicines from the vet and we checked them thoroughly for ticks when they returned to the house. We also did tick checks every morning and every evening before bed. Yet we began to find ticks on us at every turn. Even when we didn't go outdoors, we found ticks. We started removing prime tick habitats like barberry bushes and evergreen shrubbery, we kept the lawn well mowed, we applied various products like diatomaceous earth and other botanical products, yet the ticks continued to bite us. Luckily, they seemed to prefer me for some reason and bit me more often than my children. I tried to be vigilant in finding and removing them all, but that proved impossible. I could go to bed at night and not have any ticks on me. Yet when I awoke in the morning and searched again, I would find ticks stuck to my skin, sucking my blood. I removed them promptly and hoped that I was finding them quickly enough to prevent disease.

In December of 2011, a little more than a year after we had moved and began to have this terrible tick problem, I suddenly became very ill. I had a fever, severe nausea, pain and weakness in all of my muscles and joints, a headache worse than any migraine I had ever suffered, chills and sweats, and a terrible stiff neck. I couldn't even hold down water, and could barely crawl across the floor from my bed to the adjacent bathroom. The pain was almost unbearable. My physician had recently left his practice and I hadn't found a new one, so I went to urgent care after two days of this illness that was worse than anything I had experienced previously. They were stumped, and apologetically sent me home after examining me and doing some bloodwork. The next day they called and said my white cell count was very high and I needed to go to the nearest ER right away. So we went to the ER. I reported all of my symptoms, as well as the many tick bites I had in the last year and a half. They kept telling me I did not have a tick-borne disease. Eventually, they diagnosed me with a bladder infection due to my high white blood cells. I was given an antibiotic for the infection and told to follow up with my doctor. I made the follow up appointment with a new physician. He looked at all my paperwork, heard my symptoms, my history of tick bites, and said he agreed with the ER's diagnosis and treatment and that I would feel better after the antibiotics. So, I went home and tried to take them and go on with my life. My

health continued to decline over the next couple of weeks and I began to experience trouble with cognition and thinking. Just a few short weeks after I had been too sick to get out of my bed, I graduated from SUNY New Paltz Magna Cum Laude with a degree in Early Childhood Education. I was excited to be a certified NYS teacher. Instead my health kept declining.

I returned to the new physician. This time, his diagnosis was that I was suffering from allergies and needed a steroidal nasal spray which did nothing for any of my symptoms. This began a search for a physician who would listen to me that something was terribly wrong. My condition deteriorated. I continued to have high white blood cells and platelet counts, multiple vitamin deficiencies, and more and more symptoms. I couldn't keep down food, and lost over 80 pounds in less than a year. I had trouble finding words when speaking. Once an avid reader, I could no longer read as the words would swim off the page and I couldn't follow the story. I forgot how to perform routine tasks at work, and some days couldn't even remember how to get there. Given the opportunity, I would sleep for entire days at a time and still be exhausted. The pain all over my body was excruciating, and never ending, as was the nausea and the headaches. I have excellent health insurance through my husband's union employment. I thought I would find the right specialist, and they would know how to fix whatever was wrong so I could get back to living my life again. Instead, I saw over 20 different physicians over the first 3 years of my illness and found no diagnosis that fit my symptoms or responded to any prescribed treatment. I was diagnosed with various vitamin-deficiencies, chronic fatigue syndrome, and fibromyalgia. I tried medication after medication and just continued to decline. The doctors all continued to deny tick borne illness, despite my history of multiple tick bites and residence in an endemic area.

Eventually, I was bit by another tick. This time I developed an Erythema Migrans Rash, and was given doxycycline. I also finally began to test positive for Lyme disease by Elissa and Western Blot. I went through two rounds of doxycycline yet my symptoms were no better, in fact they were worse. The pain and tingling had spread to the point I could barely hold a glass in my weak hands and I had constant tremors in my fingers and toes. My general practitioner did not know what to do for me, and suggested I go to see someone in an academic setting, as they would be more likely to help. At Infectious disease at Albany Medical Center, I again tested positive for Lyme disease, Anaplasmosis, and Rocky Mountain Spotted fever. As well as a reactivation of the Epstein Barr Virus. Yet, the doctor stated that those things I tested positive for couldn't be making me ill as I had already had doxycycline so therefore they were treated, cleared, and not the cause of my illness. I was sent to neurology for an MS workup as my symptoms now seemed very much like MS. After many trips to Albany and many expensive tests that my insurance company paid for, the neurologist determined I did not have MS but neurological Lyme disease and should return to infectious disease for treatment. The infectious disease doctor reiterated that because I had doxycycline that the tick borne illnesses couldn't be my problem. He didn't know what was, but prescribed Lyrica and sent me on my way.

Unfortunately, there is now a vast body of research showing that Lyme can and does persist in up to 50% of the patients. The old idea that Lyme was hard to get, and easy to treat, has been proven wrong over and over. Still, Doctors, in areas where they should know what to look for and how to treat (like mine) missed my condition from the very beginning and then continued to ignore it while I just got sicker and sicker.

I sincerely hope that one of the issues addressed by the committee will be the lack of Physician understanding on how to diagnose and treat tick borne illness properly from the beginning. If they had treated me properly when I first became ill, these infections would not have had a chance to become chronic. I think that physicians should be required to

constantly update their educational knowledge, just as those of us in an education field like mine are required to do to keep our credentials. Mainstream physicians should be trained to properly recognize, diagnose, and treat tick borne infections before they become chronic and out of control.

After the Lyrica failed to help, I felt I had run out of options where I could seek help in mainstream medicine with my insurance. I had lost my second job due to too much missed work. Feeding my family was becoming more and more difficult. My relatives agreed to help my pay for a Lyme literate physician. He diagnosed me with neurological Lyme, Anaplasmosis, Rocky Mountain Spotted Fever, and additionally diagnosed me with Babesia and Bartonella through a clinical diagnosis based on my symptoms and response to proper treatment. I don't think any measures that do not include requiring doctors to treat us and insurance companies to pay for those treatments will be effective in stopping the spread of these illnesses, as too many people become chronic and forced to remain ill due to lack of access to care. When I first went to the Lyme specialist, I had had high platelets and white blood cells for over 3 ½ years. I had a constant fever, had been waking every morning for years soaked in sweat, had horribly low blood pressure, constant nausea and stomach pain, joint and muscle and bone pain, severe headaches, and many cognitive symptoms. I could still walk, but only very slowly and in extreme pain. He began treating my Lyme disease and my Babesia with various combinations of oral antibiotics. It helped but did not cure any of my symptoms. Then after 5 months of oral meds I got a PICC line in my arm and did daily infusions of IV Rocephin for my neuro Lyme and oral atovaquone for Babesia. Some of the worst symptoms improved. After about 5 months, my white cell counts and platelets actually went normal for the first time in almost 5 years. The tremors disappeared, and my brain became less foggy. But many stubborn symptoms still remained. When I had been on IV antibiotics for 7 months, my blood sugar suddenly spiked and wouldn't come down. The IV antibiotics had to be stopped and the line pulled. The Lyme Literate Physician was not sure what else to do for me after that, and I couldn't afford to keep paying the exorbitant fees. I continue to be horribly ill, and in fact, the symptoms that had improved while on IV medicine are now returning. My white blood cell and platelet counts increased again when the Rocephin was stopped. Now I'm struggling to find a physician who can help me, as not many know what to do with patients like me. Again, access to adequate care is a big problem for Lyme patients here in New York. This is just a shortened version of a very long saga, I can provide many more details if needed.

In addition to the illness itself I have struggled with for the last 5 ½ years, I also had to find a way to deal with all of the ticks that kept finding their way into our home. As I stated previously, we had moved into prime tick habitat. My neighborhood is very rural, with small tracts of land cut out of the surrounding endless forest land. For instance a 2003 report by the University of Michigan found that "In patches less than 5 acres, the risk of human exposure to Lyme disease was almost 5 times greater than in larger forested areas." The surrounding woods is also heavily made up of habitat shown to promote ticks, including locust trees and barberry bushes. I've removed all of those from my property, but can't remove them from surrounding wooded lots where they abound. Living so close to the 22, 275 acre Minnewaska State Park, wildlife abounds here and there is a constant stream of deer, foxes, black bears, wild turkeys, mice, other rodents, and wild birds all carrying ticks all around the neighborhood, dropping them everywhere they go.

In the Spring of 2014, very ill, unable to find proper treatment, and still being plagued by ticks, I decided to get chickens. We didn't get guinea hens as we find them to be very loud. The preschool where I worked hatched 6 chicks and in June of 2014, I brought them home, and converted a shed to a chicken coop. We quickly learned that they were indeed voracious eaters of ticks but that the 6 young birds couldn't keep up with all the ticks on our

acre and a half. We expanded, and our daughters began raising and showing chickens for 4H as well. Once we had enough chickens free ranging in the yard, we found that every single tick disappeared. And for the next 3 years, I never saw a tick at my home, and none of my children or myself were bitten. It was amazingly freeing to feel safe within our own home and yard again after several years of feeling unsafe because of all the ticks. However, living so close to a preserve, the local predators quickly showed that they thought chickens were a great snack. We learned we needed to constantly keep breeding our chickens or the predators would reduce our population too low and we would start finding ticks again. We started raising heritage breeds that were historically native to New York but now endangered. A year after we first got chickens, we also got some garden ducks to eat the pests in our garden and the mosquitos as we had found green pest control to be very effective. In June of 2015 we adopted 3 goslings. We were desperate to find a way to protect our free ranging tick eating chickens while they were busy patrolling the yard and eradicating the ticks. We heard geese were good protectors of flocks and particularly good at deterring foxes. It turned out, getting the geese would prove to be very effective at deterring foxes. It also caused a neighbor to complain to our town about our birds for the first time in the 18 months we had owned chickens.

In November of 2016, we were visited by a building inspector, and informed that the zoning laws in our rural town did not allow us to own a single bird. We could own a pig or a cow but not a single chicken, duck, or goose. We explained we had chickens to protect us from the many ticks, and that they were necessary. We visited all of our neighbors until we found our single unhappy neighbor. They didn't dislike anything expected. They had an issue with the sound the geese made when they honked. (yet our town is named after the Indian word for goose, and it is the school's mascot, as they are a native species) They said the noise interrupted them when they wanted to entertain on their deck. We assured them we didn't want to inconvenience anyone and gave them our number. We said if they called us, we would put the geese and roosters in the garage for the day so they wouldn't hear a sound. We hoped we had fixed the problem. We didn't hear anything for almost a year. In May of 2016 our landlord received a letter from the Town saying our birds were illegal and we had to get rid of them. I obtained a letter from my physician explaining that I was being treated for many tick borne diseases and that I had not been bitten since acquiring chickens and therefore needed them for my health. I brought this letter and all of my positive tests for tick borne disease to my Town Supervisor's office and explain why I needed my chickens. He promised me that they weren't going to take away my birds. He said as long as we didn't get any more birds, they would work on changing the law so I could keep the birds, and I should return home and not worry.

I listened to that advice. We complied with not getting any more birds. In fact, we rehomed the loudest of our three geese, rehomed some chickens, reduced our roosters to just two. For the next year I worked on treating my infections and we didn't hear anything else about the chickens.

Suddenly, one terrible morning in April of 2017, the Town Supervisor and Building Inspector knocked on the door. It had been almost a year since I was promised as long as I didn't get more things would be okay. Instead, they were now standing on our doorstep telling us there had been another complaint, and we had to get rid of all but 15 hens. No geese, no ducks, no roosters. No more discussion. My landlord received a letter from the Building department saying we were continuing to disregard town law and the landlord would be taken to court if we did not comply in two weeks. We tearfully rehomed all of these birds we had been raising for years and reduced our flock to the required 15 hens only. In a matter of days we were seeing ticks again all over the place. Furthermore, roosters are very important to a free-range flock. They function as protectors of the flock, keeping the hens together and warning of predators. Our remaining 15 hens quickly began to be lost to the

neighborhood foxes. Even hens that had been raised by my preschoolers at school and lived here for almost 4 years and survived every other predator attack were suddenly unable to fend for themselves without roosters to warn of danger. My son got bitten first. Then my husband, and then me. Then my daughter and then me again. Our home is once again a scary and frightening danger zone. And the only effective measure I had for protecting my family from the very real tick danger has been taken from me. My county has a campaign that says "only you can prevent tick borne disease." But how can we prevent these diseases when even rural towns are legislating out effective tick-control measures like free-range chickens and guinea hens? How am I supposed to protect my family from the little blood suckers if I am not allowed to use the only effective measure I have found to combat them?

There aren't any studies in the US on the efficacy of chickens eating ticks, but in other countries, where ticks often impact livestock, chickens have been studied quite thoroughly. For instance, in Kenya in 1991, researcher Hassan found that chickens allowed to scavenge among tick infested cattle could eat from 3 to 331 ticks in 30 minutes to an hour, with an average of 81 per chicken. And that chickens were natural predators of ticks. (references available). And in Pakistan, agricultural researcher Soomro states that "Biological control (i.e. chickens) of ticks is the most safe, effective and cheapest way and encouraged worldwide due to its safety." Yet here I am in the middle of New York's Hudson Valley in the middle of a gigantic forest in a very rural area, and I am being prohibited from keeping chickens to eat my ticks. According to the 2000 census bureau data, my town has a population of 12, 889 people and we are spread far and wide through the woods full of ticks. The population density is only 98.6 people per square mile, which leaves lots of woodland for ticks to thrive in before finding their way to my yard.

I believe that in states like mine where tick borne disease is a huge epidemic, it should be illegal for towns to legislate out tick eating chickens and guinea hens. It is the only way we have to effectively protect ourselves in this sort of prime habitat.

I hope that you will consider these important issues at the Public hearing on Lyme on Tuesday. And that the stories of those of us here in New York suffering with these terrible diseases will not be forgotten. We need to make major changes or we won't be able to slow the tick's progress.

For more info please feel free to ask me questions, or view my blog on these issues at www.ticksareforthebirds.com

Thank You,
Deborah Skogman
Concerned New Yorker Suffering with Tick Borne Disease