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March 6, 2013 – Senate Bill 0368/HB 5104 – Public Testimony

To Connecticut Public Health Committee:

Summary: My personal experience with Lyme and other Tick-Borne Diseases can be found at the bottom of this testimony. As you will note, my family's experience is not all that different than the many others who have had the unfortunate experience to face this disease and navigate the difficult process of obtaining adequate information and prompt, appropriate diagnosis and care.

Awareness (prevention), Prompt, Appropriate Diagnosis and Care… Sounds like something simple to obtain after a disease well-known to Connecticut for over thirty years.

Ironically that is not the case…

The number of Lyme disease cases in the United States has doubled since 1991. The Centers for Disease Control and Prevention estimate that there are nearly 325,000 new cases each year—**making Lyme disease an epidemic larger than AIDS, West Nile Virus, and Avian Flu combined**. Yet, only a fraction of these cases are being treated, due to inaccurate tests and underreporting. Each year, hundreds of thousands go undiagnosed or misdiagnosed, often told that their symptoms are all in their head.

**Centers for Disease Control (CDC), Infectious Disease Society (IDSA), International Lyme and Associated Disease Society (ILADS), CT Dept. of Public Health, Lyme Organizations (See Agreement Chart)

All Sources Agree (per sourced information**)	**Experience/Challenges (faced by the general public, patient/physician)**
Causes of Lyme and Tick Borne Diseases:	**Causes of Lyme Disease Misunderstood:**
Lyme disease is caused by bacterium – Borrelia burgdoferi	The white-footed mouse lives in all kinds of areas, particularly in people's yards/barns/garages/stonewalls, edges of forest.
90% Reservoir of this bacteria resides in a white-footed mouse - which infects ticks that feed on them	Many people are under the impression that care is only needed if you go for a walk in the woods. Squirrels, foxes and other animals also carry ticks, not just deer.
Transmitted to humans by bite of infected black-legged ticks	Questions arise on how long the tick needs to feed to increase risk of infection
Ticks that transmit Lyme disease also transmit other tick-borne diseases	Co-infections are not commonly known by physicians/public, so symptoms may be missed
Prevalence:	**What really is the prevalence in CT?**
Prevalent across the United States and throughout the World	CT has been the epicenter for Lyme for years… CDC acknowledges 10% underreporting
Most common disease carried by ticks in the United States, and the number of those afflicted is growing steadily—from 10,000** (100,000) reported cases in 1992 to 30,000 in 2009** Underreported 10% - 300,000 cases	CT IS an ENDEMIC area – but how many ticks are infected? With what bacteria or other tick-borne diseases are they infected with that pose a risk to human? Veterinarian reports ¼ dogs are tested positive with Lyme bacteria in Middlesex County
95% of all cases occur in the Northeast/Upper Midwest	Surveillance criteria has changed over time skewing comparison data

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All Sources Agree (per sourced information**)	**Experience/Challenges (faced by the general public, patient/physician)**
CT – 2011 reported 30,380 (based upon underreported 10% and reported 3,380 cases)	Changes in case definition for laboratory and physician reporting has changed over time skewing comparison data
25% of reported cases are children ages 5-19	Local Tick Tests have not been widely performed
Prevention/Awareness:	**How can the Unaware become Aware?**
Most humans are infected through bites of immature ticks called nymphs (size of a poppy seed)	Bites go undetected very often – so the only thing one may be aware of is onset of symptoms
Ticks can attach to any part of the body, but are often attach in hard-to-see areas; groin, armpits, and scalp.	No funding has been made available to do community-based awareness programs
A single tick bite can have debilitating consequences	An infrastructure is in place (local health departments) who are also unaware of this disease and the prevalence of symptoms
Best treatment is prevention/reducing exposure to ticks	Prevention measures (tick checks, showering, covered skin, etc) is fantastic, but not always practical. Young children run in and out all day and will not wear pants/long-sleeve shirts in the summer
Prompt Diagnosis and Treatment	**The average patient sees 5 doctors in 2 years before being diagnosed with Lyme and other Tick-Borne Diseases (lda.org)**
EARLY treatment is KEY to prevent severe illness	If tick bites go undetected, wait until symptoms appear before going to physician
If left untreated, infection can spread to joints, heart and nervous system	Physician doesn't ask about potential exposure to ticks (even though we are in an endemic area) or if the patient remembers a tick attached
Clinical manifestations most often involve; skin, joints, nervous system and heart	General practice, if symptoms are vague – is to wait and see Available information is out-dated – in need of revision
Lyme Disease is diagnosed based on symptoms, physical findings and possibility of exposure to infected ticks	If Practioner suspects Lyme, a test will be ordered Reliability of the tests are in question
Lyme Disease is a CLINICAL diagnosis	Practioner will often use Laboratory tests to DIAGNOSE or RULE OUT the disease
Laboratory testing may be helpful if used and interpreted properly	Laboratory tests are NOT all the same – case definition of positive results are reported based on surveillance guidelines
Healthcare Practitioners in endemic areas should become familiar with the clinical manifestations and recommended practices for diagnosing and treating Lyme and other Tick-Borne Diseases	Many physicians are not aware of any Lyme or other co-infection symptoms other than "achy joints" and "bulls-eye" rash. Neuro symptoms are often missed during this phase. If caught – often standard protocol of antibiotic treatment is not enough (40% often end up with life-time effects of the untreated disease)(lda.org)

"Knowing is not enough; we must apply.
Willing is not enough; we must do."
Johann Wolfgang von Goethe –
Scientifically and politically minded literary artist

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2013 Legislative Proposal: - Senate Bill 0368 and combine House Bill 5104

1. Scientifically Diverse Lyme and Tick-Borne Disease Advisory Committee
   (The language in the bill MUST ensure broad spectrum AND MUST include patient representatives)

2. Review Major Gaps in Understanding the Tick-Borne Diseases

3. Identify Opportunities for:
   a. Coordination of Efforts between agencies/communities and organizations
   b. Additional Funding for Community-Based Programs for Awareness, Physician Awareness, Research and Prevalence testing

4. Report on Findings and Make Recommendations based upon those findings (see VA Lyme Disease Task Force Final Report)

5. Reporting from CT DPH – incorporating two standards of care throughout…
   a. Annual Public Reporting of grants/funding dedicated to Lyme and Tick-Borne Diseases (including community-based awareness programs)
   b. Annual Statistical Reporting
   c. Consistent and updated information on Website regarding disease and associated risks (easily accessible for the unaware)
   d. Coordinated Awareness – State Parks, Schools, Local Communities, etc.

Respectfully Submitted; March 7, 2013
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Personal Experience – Myself (symptoms started 3/2012 – currently being treated 3/2013)

Infected after playing ball with my children in our front yard in Middlefield. Aching/crackling neck, progressing to shoulders, upper arms, back, hip and right thigh. Muscle twitches/pulses and atrophy, delayed motor skills, slowed speech, slurred speech, muscle weakness, cognitive barriers, double vision (images overlaid), decrease in hearing, ringing in ears, sensitivity to noise, increased irritability, decrease cognitive stamina, not able to spell or speak the right words, unmotivated, migraine headaches, began falling, unable to do anything quickly or concentrate for any extended period of time, right knee/leg felt swollen(big), SPECT scan revealed decrease in blood flow in areas of brain.

Initial visit to general Practioner; tested for Lyme, arthritis and MRI (m.s.)… Per physician, Lyme titer was "negative", recommended a neurologist. In meantime, went to Naturopath, felt symptoms were consistent with Lyme and tested again. The test then came back positive with two I'm (even according to CDC). Called Physician and faxed new results, 4 weeks Doxyclycline ordered. Neurologist confirmed that infection spread through spinal cord based upon symptoms, but was certain that 4 weeks Doxyclycline would be sufficient. I didn't start Doxyclycline until about 8 weeks after initial infection.

By the 4th week, I was symptom free on the Doxyclycline. I knew I couldn't get any more antibiotics from my physician, but also knew-based upon my daughter's experience, that this might not be enough. Sure enough – two weeks after going off the Doxyclycline, all symptoms returned, although not as intense at first, but more severe and systematic overall.

After Lyme Literate Doctor Visit, put on oral antibiotics, but progress slow and worried about decrease blood flow in brain (per SPECT Scan) and consistent cognitive dysfunction. IV therapy ordered – I am nearly symptom free currently (after 10 weeks) while on IV and feel much better. Able to maintain cognitive stamina and seamlessly do the things that became very difficult (e.g. like making a bed, speaking intelligently, spelling).

I KNEW about Lyme disease and KNEW who to go to, and STILL couldn't get treated quickly enough. It is about one year since my symptoms began. I hope that I will be able to recover fully from this ordeal so that I can better take care of my family and balance my work/social life.

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Personal Experience; Marie L. Benedetto – daughter infected

Lyme/co-infected daughter, undiagnosed for 6 years (Age 5 to current age 13)

Symptoms: Chronic fatigue/stamina issues, night sweats, vision, hearing issues, cognitive/fogginess issues, lower body temperature, sleep issues, continued illness, walking/balance issues, food sensitivities, compromised immune system, fevers, neurological dysfunction/weakness on right side of body, excruciating burning shooting pains, paralysis of leg, arm, face, feet, temporary blindness, numbness, memory loss, at times unable to walk or talk, unable to attend her entire fourth-grade year at school, misconception about her academic abilities, etc. etc. A LOT of issues for a young girl that may have been avoided…Reinfection in November 2012, caused tremors, numbness in left hand, feet, legs... in addition, anxiety and social withdrawal from friends.

Treatment from medical community – passive, not knowledgeable, unwilling to link symptoms holistically, general disregard, implied mental illness, even with knowledge of tick bite and risk factors, when diagnosed with Lyme Disease – many medical professionals wouldn't even use the word or acknowledge you. They wouldn't even write it in the medical records even after you told them the history…even after you gave a positive lab report (even according to CDC positive)…

Our actual detailed story of our challenges with the local medical community would send shivers down most parents' spines.. and they would **never** again go to a doctor without using their own sense of self-advocacy armed with knowledge and maintain their own medical history.

Costs Associated: We have spent tens of thousands of dollars (I have actual numbers for submission if you wish) of our own money as insurance companies do not always cover the medical specialty of which is needed to fight this disease. The insurance company has also paid a great portion of various bills adding to the surmounting cost of this disease to our family. If the information was generally accepted and available at the time my daughter became ill, a pediatricians' question "Has she been bit by a tick in the recent past" may have been asked and all of this could have been prevented with a $25.00 bottle of antibiotics. There is no measurable cost to the pain and suffering my daughter (and our family) has endured for the past eight years.

Final Treatment – We needed to go out of state (**New York City**) – it appears if anywhere from New Haven County and North in CT (at the time)– absolutely NO acknowledgement whatsoever that there is even the remote possibility you can contract LYME disease/co-infections.

Received treatment with antibiotics (oral and IV) (3 yrs of treatment) and holistically treated to support immune, endocrine, and nervous system. **Co-infections are significant in her diagnosis and treatment**. She is currently doing well in school, has more stamina, better concentration, stronger immune system. Unfortunately due to the **prolonged disease**, some **permanent damage** may have been done (thyroid and nerve damage) and will continue to have to be monitored for relapses (due to how the bacteria can hide and wait for an opportunity) and then will be treated. She is left with memories of her childhood being ill, in pain/incapacitated at times. Now our fears lie ahead of relapse and will she pass this on in utero should she have a child in her future…it is a possibility that we don't want to face…

Next Steps: Now that my daughter is on a seemingly positive healthy path – I have more time to dedicate my energies to improving the process, awareness and overall good health of the citizens of Connecticut. I want to help the individuals and families avoid the challenges and hurdles we faced in finding the appropriate medical care needed for our daughter. It is devastating to the families and not to mention the victim herself. No child or citizen in the State of Connecticut or anywhere for that matter should have to undergo the scrutiny and general disregard of the medical community that we had to face.

People have sought me out with their own challenges facing them with similar symptoms, stories… I can name over 30 individuals alone who have sought me out in the past year (even perfect strangers) that have the same story…A most powerful realization that came to me in 2009 when my daughter was first diagnosed when I attended a local symposium in Glastonbury to learn more about Lyme Disease. Over 300 people attended this local event, all strangers in the room, yet linked together with the same story…we all experienced similar symptoms, similar medical community pushback and disregard… How can we all be CRAZY? These were just 300+ local people who happened to hear of the event, and happened to be able to make it to the event…all with similar symptoms and stories… That is statistically significant to me.

My hope is that we can come together and provide the awareness necessary to protect the health of our citizens.