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My name is Karen Gaudian from the Ridgefield Lyme Disease Task Force. I would first like to Thank Representative Sayers, Senator Handley and the members of the Public Health committee for allowing us this opportunity. I would also like to Thank Jason Bartlett for taking on such a difficult and controversial subject!!

All 4 members of my family have been infected with Lyme disease, all four of us presented with different symptoms. We did not get this while hiking in the woods or walking in tall grass; we got this from working and playing in our yard. We also have a variety of tick-borne co-infections; my youngest daughter has tested positive not only for Lyme disease but PCR positive for Babesia, bartonella and mycoplasma fermentans. None of us meet the CDC criteria for lab reporting.<sup>1</sup>

My oldest daughter was first diagnosed when she was in third grade; it is now seven years later. She has struggled in and out of school ever since, missing over 4 ½ years. It is very difficult for people to understand what this means. She has suffered from debilitating headaches, extreme fatigue, vertigo, and cognitive dysfunction. Light is kept low as it increases the pain, common noises can be devastating; the clicking of a clock, tapping of a finger or pen or the sound of a spoon on the cereal bowl can cause her to scream in frustration. Smell can also be a problem; it reminds me of being pregnant, perfumes, chemical odors, and food; smells that most of us would barely notice. I should clarify the word fatigue as I know what it brings to mind when I hear it and it is not what I have experienced or witnessed with my children; it is a fatigue that causes the simple act of taking a shower to become a task that will wipe you out for the rest of the day. We are blessed with a child that is a 'chronic reader' we have to pull the books away from her in order to get her to eat dinner with us, she spent over 6 months unable to read as she could not remember the word she had just read in order to track the story. A simple math problem such as  $2 + 2$  can not be accomplished because she is simply unable to keep the information in her head. When she was at her worst she spent her days in her room, shades drawn, staring at the ceiling, unable to escape the pain and excruciating boredom with a book or even TV. She has missed some of the most significant developmental years of her childhood unable to interact with peers or friends. She has been unable to participate in sports, or any of the other normal childhood activities and social events other children and their parents take for granted; even just 'hanging out' with her friends is often to difficult. These children become a shadow of themselves; forgotten by their friends and the schools.

Education for a child with chronic neurologic Lyme disease is a nightmare. We were stunned by the treatment we received from the school system. Instead of compassion and support for a child suffering from a severe bacterial infection in her brain we were treated with doubt and suspicion; demands were imposed upon us that were impossible to keep. We eventually were forced to hire a lawyer not to sue the school but so we could get some work for her; it was January and she had received no material from one of her classes since the beginning of the school year, not one work sheet.

Our schools have been given no direction in regards to this disease. They are unable to understand the fluctuation of symptoms or why a child does not 'look sick'. The social impact of this disease is horrific; children are met with doubt from teachers and their peers. My daughter allowed to recover; was very excited to return to school and more importantly excited to return to a 'normal' life. I am very happy to say she is now a sophomore at Ridgefield High School taking two classes in school, tutored for two more at home and currently has a 4.2 GPA!

Due to the lack of information at a state level schools continue to send students into high risk areas at peak tick season unaware of the dangers they are placing our children and teachers in. We have a wonderful course in Ridgefield called the Norwalk River Study Program, where over 500 4<sup>th</sup> grade children, staff and volunteers go out into a highly infested area at peak tick season, October and May. They return from these trips crawling with ticks. What would possess a school medical advisor to ignore repeated requests to add disease and prevention information to the permission-slip?

When my daughter was in 6<sup>th</sup> grade and starting to decline again; having missed a sizable chunk of school I remember having a meeting with one of her teachers. He told me how great she was at making up her work and even though he had offered her more time she never took it. I was so proud of her knowing how hard she struggled to accomplish this. But then he told me "I had a student last year who was constantly taking advantage of his illness, saying he was too sick to make up his work." I felt terrible for this child, the teacher was unaware of the huge differences in the way this illness can impact a person, he thought this other child was 'milking it' and the fact that my daughter was able to function well on some days only confirmed his suspicions. Unfortunately she went on to miss the next two and a half years of school. This disease affects everyone differently; symptoms vary greatly person to person.

The way in which children sick with Lyme disease are accommodated varies greatly district to district as well as teacher to teacher. It also varies doctor to doctor. There is a heated debate going on in the medical world over how best to treat this disease; until this issue is resolved we can not continue to punish our children for becoming infected with these bacteria. There is a huge disconnect in the information being distributed throughout this state; three health districts have been receiving education and prevention materials for 20 years while the rest of us have been left to our own devices. It is time for the CT Department of Public Health to address this devastating disease; the largest vector borne illness in the country, before any more of our children have their lives stolen from them because of the bite of a tiny little tick while playing in the yard.

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## Lyme Disease Surveillance Case Definition

*A surveillance case of Lyme disease is defined as follows:*

1. A person with erythema migrans of at least 5 cm in diameter;

OR

2. A person with at least one later manifestation and laboratory confirmation of infection.

**NOTE:** *It should be emphasized that this is an epidemiologic case definition intended for surveillance purposes.*

### General Definitions:

- 1) **Erythema Migrans (EM):** For purposes of surveillance, EM is a skin lesion that typically begins as a red macule or papules and expands over a period of days or weeks to form a large round lesion, often with a partial central clearing. A solitary lesion must reach at least 5 cm (2 inches) in size. Secondary lesions may also occur. Annular erythematous lesions occurring within several hours of a tick bite represent hypersensitivity reactions and do not qualify as EM. In most patients, the expanding EM lesion is accompanied by other acute symptoms, particularly fatigue, fever, headache, mild stiff neck, arthralgias, or myalgias. These symptoms are typically intermittent. The diagnosis of EM must be made by a physician. Laboratory confirmation is recommended for persons with no known exposure.
- 2) **Late Manifestations:** These include any of the following when an alternative explanation is not found.
  - a) **Musculoskeletal system:** Recurrent, brief attacks (weeks or months) of objective joint swelling in one or a few joints sometimes followed by chronic arthritis in one or a few joints. Manifestations not considered as criteria for diagnosis include chronic symmetrical polyarthritis. Additionally, arthralgias, myalgias, or fibromyalgia syndromes alone are not accepted as criteria for musculoskeletal involvement.
  - b) **Nervous System:** Lymphocytic meningitis, cranial neuritis, particularly facial palsy (may be bilateral), radiculoneuropathy or rarely, encephalomyelitis alone or in combination. Encephalomyelitis must be confirmed by showing antibody production against *Borrelia burgdorferi* in the cerebrospinal fluid (CSF) demonstrated by a higher titer of antibody in CSF than in serum. Headache, fatigue, paresthesias, or mild stiff neck alone are not accepted as criteria for neurologic involvement.
  - c) **Cardiovascular System:** Acute onset, high-grade (2<sup>nd</sup> or 3<sup>rd</sup> degree) atrioventricular conduction defects that resolve in days to weeks and are sometimes associated with myocarditis. Palpitations, bradycardia, bundle branch block, or myocarditis alone are not accepted as criteria for cardiovascular involvement.
- 3) **Exposure:** Exposure is defined as having been in wooded, brushy, or grassy areas (potential tick habitats) in an endemic county no more than 30 days prior to the onset of EM. A history of tick bite is not required. All Connecticut counties are endemic for Lyme disease.
- 4) **Laboratory Confirmation:** Laboratory confirmation of infection with *B. burgdorferi* is established when a laboratory isolates the spirochete from tissue or body fluid, detects diagnostic levels of IgM or IgG antibodies to the spirochete in serum or CSF, or detects significant change in antibody levels in paired acute and convalescent serum samples. Syphilis and other known causes of biologic false positive serologic test results should be excluded as appropriate, when laboratory confirmation has been based on serologic testing alone.

## **Cognitive impairment in Lyme disease: specific functions and the impact or deficits**

1. *Attention and mental tracking*: includes directed and sustained attention: the ability to direct and maintain one's focus on a particular event or idea, whether in the environment or internally; and divided attention: the ability to simultaneously attend to two events, or do two or more things at a time, or to retain awareness of one thing while doing another.

Impact: difficulty functioning effectively in many situations, remembering what one was doing before a distraction, keeping track of conversation, taking notes while someone is speaking, remembering that someone is on hold or what you were about to say

2. *Memory*: Retaining new information

Impact: secondary to impaired attention, slowing of processing and the retrieval of stored information, but not storage per se, a tendency to lose or forget things, miss appointments, repeat oneself

3. *Receptive language*: understanding spoken or written language

Impact: secondary to impaired attention and speed of processing, difficulty participating in meetings or social conversation, difficulty with reading comprehension

4. *Expressive language*: Using spoken or written language to express ideas

Impact: difficulty finding the right word, using the wrong word and not noticing, not being able to express oneself or communicate

5. *Visuospatial Processing*: Efficient scanning of the visual field, making sense of how things are related in space, visuospatial conceptualization and problem solving

Impact: a tendency to get lost, difficulty with reading comprehension

6. *Abstract reasoning*: The ability to generalize from the particular, to identify the common factor between related concepts, to compare and contrast two things or ideas, to see the "big picture", to identify the critical factor in a situation, to anticipate consequences and make inferences regarding cause and effect

Impact: difficulty with decision making, planning, and problem solving

7. *Speed of mental and motor processing*: the ability to think and respond quickly, critical to understanding speech which occurs at a fairly constant rate

Impact: difficulty understanding or keeping up with conversation, functioning in a timely manner in day to day situations, meeting deadlines

**(Source: Cognitive Characteristics of Distinct pattern of cognitive impairment noted in study of Lyme patients by Marian Rissenberg, Ph.D. & Susan Chambers, M.D. – American Psychiatric Association conference presentation – 1996.**