

THE EFFECTS OF LYME DISEASE ON CHILDREN IN SCHOOL  
ENHANCING THE KNOWLEDGE BASE OF SCHOOL PROFESSIONALS

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I dedicate this study to all Lyme sufferers, past and present. To your bravery, strength, perseverance and fierce determination to fight to regain your life back from chronic Lyme disease. I also thank my friends and family who have supported me, loved me, and stood by me during my many trials with Lyme. Special thanks to the few extraordinary people in my life who have blessed me by continuously giving me God's word throughout the course of this project and providing me with support and encouragement while always believing in me! Thank you!

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## ABSTRACT

### THE EFFECTS OF LYME DISEASE ON CHILDREN IN SCHOOLS ENHANCING THE KNOWLEDGE BASE OF SCHOOL PROFESSIONALS

by Amanda Lee

Lyme disease is the most prevalent tick-borne vector disease in the United States. Found in all 50 states, Lyme disease affects people in all environments. Children comprise the greatest percentage of those with Lyme. The effects of Lyme on children can impact their educational performance and abilities. They also may present with behavioral problems or absences as they may suffer from many different symptoms. The purpose of this thesis is to provide a set of materials for use in school districts, to educate school professionals on the basic knowledge of Lyme disease and to show how it impacts children in school. A packet of information, including a powerpoint presentation, describes Lyme disease, prevalence in general, prevalence in children, prevention, and Lyme symptoms seen in the school environment. A list of resources that can be used to learn more information on Lyme disease is included, along with a short checklist of Lyme symptoms. This packet of materials has not been dispersed and used in the school environment, which is a limitation current practices in most schools. This packet of materials could be used to put together an in-service on Lyme disease for school professionals. There could be a great benefit to expanding on this package of resources describing Lyme disease and creating a curriculum to be used school or district-wide to provide greater education and prevention among children and professionals.

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## CHAPTER I

### INTRODUCTION

Lyme disease is caused by the bacterium, *Borrelia burgdorferi* (Bb). It is spread by the bite of an infected tick. *Borrelia burgdorferi* is a bacteria called a spirochete, as it has a spiral shape, which allows it to burrow into tissues and get deeper into a person's body. It is the most common vector-borne, infectious disease in the United States of America (Gerber, Shapiro, Burke, Parcels, & Bell, 1996). A vector-borne disease is an infectious disease spread through blood sucking insects such as mosquitoes, ticks, biting flies, etc. It is growing at a rate four times faster than HIV/AIDS, according to the Center for Disease Control and Prevention (CDC) (Children's Lyme Disease Network [CLDN], 2012a). It is an epidemic and also a pandemic, found in every continent in the world (Harvey & Valato, 2003; International Lyme Disease Association, 2011). Lyme disease has been found in more than 80 countries worldwide (Lyme Disease Association, 2013). The CDC World Health Organization Coordinating Committee indicates, "[Lyme Disease] is focally endemic in North America, Europe and Asia, and is probably the most common tick-borne bacterial disease in the world. In the United States, Lyme disease accounts for more than 90% of all reported cases of vector-borne illness." Lyme has been found in every state in the United States and causes a variety of symptoms. Some common symptoms, among many others, may include different types of pain, severe fatigue, difficulty having restful sleep, headaches, forgetfulness/memory loss, difficulty with thinking and concentration, depression, anxiety, and problems with the eyes, ears, heart, bladder, and brain such as neurological problems. Lyme disease is also passed in utero, from mother to child (Grier, 1997). Many young children with Lyme disease present different needs and problems in the school environment.

## Impact of Lyme Disease

Lyme disease is called the "Great Imitator" (Meyers & Burrows, n.d) as it is known to mimic over 200 different conditions, including, but not limited to, Fibromyalgia, Arthritis, Juvenile Arthritis, Attention Deficit Hyperactivity Disorder (ADHD), Lupus, Amyotrophic lateral sclerosis (ALS), Parkinson's Disease, Alzheimer's Disease, Multiple Sclerosis (MS), Chronic Fatigue Syndrome and Autism (Weintraub, 2008a). Lyme disease is a pervasive disease that can be very debilitating when left untreated. An untreated person who has this infection can develop Chronic Lyme Disease, also known as Late Disseminated Lyme (Burrascano, 2008).

## Lyme Transmission

Lyme is generally contracted through contact with a deer tick, although there are other ticks that also spread Lyme. Ticks can be found almost anywhere; they are in suburban areas as well as wooded areas. They are spread by deer, migrating birds, mice and other small animals (CLDN, 2012c). Ticks can carry and transmit various diseases and the host is then often infected with "co-infections" (Lang & Liegner, 2004). The most typical co-infections include Babesia, Ehrlichia, and Bartonella. There are many overlapping symptoms between these conditions. Ticks inject their saliva into a person or host, which transmits the infections they are carrying. According to Goss (2012), a tick can transmit infection after being attached for just a few hours (CLDN, 2012c). Others, however, disagree and believe a tick must be attached for a minimum of 36 or more hours (Wright, Riedel, Talwani, & Gilliam, 2012). Therefore, research is inconclusive on this issue. When a tick feeds on a host, it becomes engorged with blood, and the initially flat tick will visibly be larger and round. According to the Children's Lyme Disease Network (CLDN, 2012c), ticks do not need to be engorged to have transmitted the disease,

however, there must be a bite from an infected tick. Tick bites are painless and it is common for a person to never see the tick or know they were bitten.

Lyme disease is known for its classic erythema migrans or EM rash, better known as a "bull's-eye" rash, as a symptom of an infected tick bite. These rashes occur in some cases; research varies as to what percentage of people display this rash. Dr. Charles Ray Jones, a leading pediatric Lyme Literate Medical Doctor (LLMD), has treated over 4,000 children of all ages, and has had only approximately 7% of his patients display a rash (CLDN, 2012b). However, a study consisting of 201 Lyme patients with a median age of 7 years old showed that 66% of patients had the bull's-eye rash (Gerber et al., 1996). Yet other reports suggest only a third of people have any rash (Buhner, 2005).

### The Detection of Lyme Disease

Detection of Lyme disease can be difficult, especially if a person does not see an attached tick. The nymphs, or smallest of ticks, are compared in size to that of a poppy seed or the tip of a pencil. Due to their small size, they can be difficult to notice. If a bull's-eye rash is present, a person is far more likely to be treated for Lyme disease in its beginning stages, as it is a classic sign of a Lyme infection. Unfortunately, one cannot rely on the presence of this rash to determine if they have been infected. During this period, Lyme is in the blood, and easier to detect via blood work, according to Igenex Laboratories (Goss, 2013). For diagnostic testing, one of the most common and accurate tests available is the Western Blot. Although it is widely used and recommended, it still presents many false negatives (International Lyme and Associated Diseases Society [ILADS], n.d; Lyme Disease Association, 2008). As time passes, and the infection progresses, it moves into the body's tissues, organs, etc., and it is more difficult to get a

positive blood test as fewer bacteria are in the blood stream (Donta, 2012). Lyme disease is a clinical diagnosis; therefore, blood tests are not necessary for diagnosis (CDC, 1999).

### Lyme Disease Prevalence

The Center for Disease Control completed a study that determined there are 300,000 new Lyme cases each year (CDC, 2013). The Children's Lyme Disease Network (2012b) considers Lyme to be one of the most dangerous infections for children. The incidence of Lyme disease is highest among children (Gerber et al., 1996). Children under the age of twelve comprise 50% of all reported Lyme cases (Lang & Liegner, 2004). According to the CDC, children ages 5-19 are at the highest risk for Lyme disease infection and claim children comprise 25% of all Lyme cases regarding this as three times higher than the average of all other age groups (Lyme Disease Association, 2012).

### Need for School Involvement

As referenced above, children have a high incidence of Lyme disease during their school-age years. During these years, Lyme disease can greatly interfere with a child's ability to learn and function in the school environment. Their symptoms can vary from fatigue to cognitive difficulties. This can make it difficult for children to make it to school, and to learn while they are in school. For these reasons, it is critical that school professionals become educated on Lyme disease. School psychologists in particular are important to focus on, as they can determine what interventions a child may need to be successful in school. With parent and school involvement and education, Lyme disease could be detected earlier, and for those children in treatment, they can be better accommodated while at school. Because of the lack of information in schools about Lyme disease, it is important to provide information and training to school personnel. This

project aims to develop materials that can be used by school psychologists or other professionals to increase Lyme disease awareness in school personnel.

## CHAPTER II

### LITERATURE REVIEW

In this literature review, information regarding Lyme disease and ticks that is important for school personnel to understand will be discussed.

#### How to Prevent Tick Exposure and to Safely Remove Embedded Ticks

Wearing light colored clothing when hiking through wooded areas helps make spotting ticks much easier. Tucking pants into socks helps prevent ticks from getting to the skin. Wearing long sleeve shirts along with long pants also helps to protect the body from tick exposure (Gerber et al., 1996). Attempting to walk in the center of a trail is important as ticks like low level grasses and shrubs, especially near the edges of wooded areas (Lachenauer, 2009). Lachenauer (2009) suggests that parents check their children frequently for ticks, especially in the armpits, backs of knees, groin areas, and scalp. When using insect repellent, DEET is an ingredient that is effective against ticks (Wright et al., 2012). The Mayo Clinic (2012) suggests using an insect repellent with at least 20% DEET. The maximum percentage currently recommended for infants and children is 30% (Lachenauer, 2009). Other products that are registered can be found on the Environmental Protection Agency's (EPA) website.

Ticks should always be removed with a pair of tweezers. Grabbing the tick near the head, as close to the skin as possible, and pulling it out, is the safest way to prevent infection, if infection transmission has not yet occurred. When a tick moves out of the body by itself, initiated by using other methods, it is likely to inject infectious fluids into the human body. Some immediate side effects that would signify an infection would be fever, flu like symptoms, muscle

aches and pains, headache and fatigue and/or a bulls-eye rash. These may develop in hours to days following the bite (Healy, 2000).

### The Different Stages of Lyme Disease

There are three stages of Lyme Disease (Beaujean, Mathieu, Bults, Van Steenbergen, Antoine & Voeten, 2013; Wright et al., 2012). The beginning phase of the disease, or Early Localized stage, refers to 3-30 days post-tick bite. Common symptoms during this early phase include fatigue, chills, fever, headache, muscle and joint pains, swollen lymph glands and potentially an EM rash. It can be treated with a short term course of antibiotics lasting 2-4 weeks (Healy, 2000; Wright et al., 2012).

The second stage of Lyme Disease is referred to as the Early Disseminated Stage. This occurs days to weeks post-tick bite. When left untreated, the bacteria can spread to any area of the body (Gerber et al, 1996). Some symptoms may come and go, or even seem to be on a cycle. Some symptoms that may present themselves during this period could include:

- Rashes that come and go on different parts of the body
- Bell's Palsy
- Severe headaches, neck stiffness, possible meningitis
- Pain and swelling in the large joints (such as knees)
- Shooting pains
- Heart palpitations, change in heartbeat

The third stage of Lyme Disease is called the Late disseminated stage, or Chronic Lyme disease. This occurs months to years post-tick bite. During this stage,

people with an untreated infection may develop many other symptoms and conditions. For example, arthritis with severe joint pain and swelling is common. The large joints are often affected. As well, neurological symptoms may begin in some people. This includes short-term memory problems, shooting pains, numbness and tingling in the extremities, amongst many other symptoms (Buhner, 2005; Healy, 2000; Wright et al., 2012).

### Parental Acceptance

All parents have hopes and dreams for their children. When a child has Lyme disease, their symptoms can change the activities the family is used to doing together, and can greatly alter the family's functioning. Parents can be advocates for their children when it comes to the school district. They can work with school professionals to determine their child's specific needs. Parents may also need to change their expectations. Children need support in all areas of their life. It is important that parents believe their children, advocate for them, and provide them with support and encouragement (Berenbaum, 2003; Lang & Liegner, 2004).

### Difficulties in School-Aged Children

#### Risk Factors for School-Aged Children

Children may have a greater risk of developing Lyme disease because they have greater exposure during outside activities (Donta, 2012). Activities such as playing in the woods, interacting with pets, and playing in the leaves put them at higher risk. This includes a lack of tick checks after spending time in environments with a higher exposure to ticks. Other contributing factors include a lack of recognition of signs and symptoms of Lyme disease by both parents and physicians (Smith, 2010).

## Difficulty in Treating Children

Dr. Charles Ray Jones, L.L.M.D., a leading Lyme-Literate pediatrician in the U.S, stated the following in Cure Unknown, written by P. Weintraub (2008a).

"We all know that children with a delay in diagnosis or inadequate therapy can be difficult to treat. No study has ever shown an optimum time for treatment, or that two to six weeks of antibiotics always results in eradication of the bacteria or a cure. But, there is ample peer-review literature that *Borrelia burgdorferi* spirochetes can survive antibiotic treatment, for one to six months or longer. We know there are more than 300 strains of these bacteria, and that different strains cause different symptoms and require different treatment strategies. Persistent symptoms indicate persistent infection."

Although Lyme can be difficult to diagnose and treat at any age, it can prove more challenging in children for the following reasons:

- Children may have difficulty communicating how they are feeling.
- A child may not recognize that a "symptom" or "feeling" is not normal.
- Joint pain can be dismissed as growing pains.
- Most children do not have an established medical history; therefore it is difficult to compare what they are experiencing to what is normal for them. There usually are no baseline data.
- Children go through different phases, and because symptoms can come and go or get better or get worse, it makes it more difficult to recognize. Symptoms can be overlooked or dismissed by attributing it to phases in a child's life (e.g. teenagers having mood swings). Sometimes children will manage to hide their symptoms at school, as they are trying to mask them. When they get home they suddenly express symptoms, and this can lead to confusion and the belief that a child is acting out or poor parenting is taking place.

- Children may be accused of wanting attention, faking their symptoms, having growing pains (as referenced above), wanting to get out of homework or household chores, or malingering. (CLDN, 2012c; Lang & Liegner, 2004)

As mentioned earlier, Dr. Jones reported that Lyme tests should be used as a backup, but not relied upon for diagnosis. His experience is that cases which are clinically clear can have a very low incidence of positive lab tests. He has found there to be high rates of false negatives (i.e. when a child is actually positive), which explains why basing a diagnosis on clinical symptoms is so important. He has said, "I have never seen a false positive" (CLDN, 2012b). The guidelines for diagnosing Lyme, by the CDC, indicate that Lyme disease is a clinical diagnosis, therefore not based on laboratory testing (CDC, 1999).

Dr. Jones has found that the primary organs impacted by Lyme include the brain, the central nervous system, the digestive tract, the urinary tract, the joints, the muscles, and the skin and eyes (CLDN, 2012b). Lyme disease is a multi-system disease that can invade any organ in the body, and often multiple organs (Grier, 1997). Some symptoms like sensitivity to light and sound are from the effect on the brain that then had an effect on the sensory system. It also can cause problems with the voluntary and involuntary motor systems. It can cause physical, emotional, and cognitive problems as it affects these areas. A child could present with symptoms in one area, multiple areas, or symptoms that move between different areas. According to Dr. Jones, a child will usually present with at least 4 symptoms (CLDN, 2012b). Because of the transient symptoms, they can vary hour to hour, change in intensity, and wax and wane. In children, neuropsychiatric symptoms can be a predominant symptom (Adams, Rose, Eppes & Klein, 1999). This can include difficulty concentrating, irritability, mood swings, oppositional behavior, anxiety disorders, obsessive compulsive disorders, depression, and Attention Deficit

Hyperactivity Disorder (ADHD). According to the CDC, children are bitten by ticks around the head and neck most frequently, hence, this makes them more vulnerable to infections of the brain and central nervous system (Lyme Disease Association, 2012). The neurological symptoms that occur from these infections are often misdiagnosed. Dr. Jones has compiled a list of common symptoms of infection from his young patients, and some of these symptoms have been mentioned earlier (CLDA, 2012b; Lyme Disease Association, 2012).

- Severe fatigue unrelieved by rest
- insomnia
- headaches
- nausea, abdominal pain
- impaired concentration
- poor short-term memory
- inability to sustain attention
- difficulty thinking and expressing thoughts
- difficulty reading and writing
- being overwhelmed by schoolwork
- difficulty making decisions
- confusion
- uncharacteristic behavior
- outbursts and mood swings
- fevers/chills
- joint pain

- dizziness
- noise and light sensitivity

He has also documented congenital or gestational Lyme disease in some children infected in utero or by breastfeeding. Symptoms that raise his suspicion include:

- frequent fevers
- increased incidence of ear and throat infections
- increased incidence of pneumonia
- irritability
- joint and body pain
- poor muscle tone
- gastroesophageal reflux
- small windpipe
- cataracts and other eye problems
- developmental delay
- learning disabilities
- psychiatric problems

(CLDA, 2012b; Lyme Disease Association, 2012)

#### Interference with Education

As the development of Chronic Lyme (or Late Disseminated Lyme) can cause problems emotionally, physically, or mentally, it can prove to be a severe problem in the school environment.

Not only do children with Lyme disease present with an array of symptoms, but fatigue is a predominant symptom that can interfere with school. Children with severe fatigue may be unable to attend a full day of school. Physical education should be considered, to address restrictions or adaptations to activities that may be necessary. Rest periods are also an accommodation that can be made during the school day. For other students, homebound instruction will be necessary (Healy, 2000).

The CDC conducted a study in New Jersey comprised of 64 school aged children with Lyme disease (CDC, 1992). The following are the results:

- Median duration of illness at the time of interview was 363 days
- Mean number of school days missed due to severe illness was 103 (range of 2-548 days)
- Median days of home instruction was 98 days (range 5-792)
- 78% of parents reported their child had a drop in grade point average during this time of illness

The length of time for which the study took place was not reported, nor was the age range of the children.

A 2008 study at the Columbia Teacher's College and the NYS Psychiatric Institute of 25 adolescents with Lyme disease and 25 matched controls (McAuliffe & Brassard, 2008), found the Lyme group had deficits in cognition, including short-term visual memory, short term and delayed verbal memory, and all forms of recognition. As well, they were found to have worse attendance, grades, and subjective reports of memory problems. Deficits in visual memory were greater than deficits in verbal memory. They concluded that adolescents with a history of Lyme disease are at risk for long-term problems in cognition and school functioning.

Children with Lyme may be out of school for extended periods of time, which can require a local district to re-examine board policies. Having these absences which can last months to even years is isolating to children. It can make them an outcast amongst their peers. A CDC study concluded that 79% of children had a decrease in their number of friendships (CDC, 2012). They conclude that allowing even minimal school interaction will help prevent school phobia, and make the transition back into the school environment easier, when the child is well enough to attend.

In 1992, New Jersey passed a law requiring the NJ State Department of Education and the Department of Health to develop state-approved school curriculum guidelines for Lyme disease (Smith, 2010). The law requires a yearly in-service for educators that have students with Lyme disease. New Jersey is the only state that has adopted such guidelines (Smith, 2010).

To help identify Lyme in schools, a list has been compiled for teachers, school nurses, and school counselors, to help them identify undiagnosed Lyme in children (Berenbaum, 2005)

Table 1. Symptoms of children to be recognized by teachers, nurses and counselors

<u>The Teacher</u>	<u>The Nurse</u>	<u>The Counselor</u>
Lethargy, Fatigue	Frequent Headaches	Difficulty maintaining a full schedule
Moody, anxiety, depression	Joint pain, twitching	Erratic attendance, tardiness
Withdrawal from peers	Dizziness, disorientation	Difficulty remaining in class
Headaches or other physical complaints	Sensitivity to light, sound or other stimuli	Decline in academic performance
Behavioral problems	Sleep disturbances	Behavioral problems
Speaking and writing difficulty	Visual problems	Withdrawal from peers
Declining attendance	Severe PMS	Change to lower functioning peer group
Poor concentration, memory	Profound fatigue	
Difficulty remaining in class	Depression, anxiety, and mood swings	
Declining Grades	Gastrointestinal Symptoms	
Erratic Academic Performance		
Attentional Disorders		
Early morning absences		
Tardiness		

Neurological and neuropsychological symptoms can have the greatest effect on learning (Adams et al., 1999). Many symptoms have been listed above, although severe headaches may

last for several days, fatigue can be profound, and sensitivity to fluorescent lighting may be present (Berenbaum, 2003). Students may look like they are day dreaming, or avoiding school work to a teacher who does not know they are dealing with a sick child.

As a child begins antibiotic treatments, other difficulties in the school environment can emerge. Antibiotic treatment can cause gastrointestinal problems, especially in high doses (Healy, 2000). A child experiencing this may complain a lot about stomach aches and be very uncomfortable. As antibiotics kill off the spirochetes in the body, there is a flare in symptoms as toxins are released into the blood stream. This is referred to as a Jarisch-Herxheimer reaction or a herx for short (Goss, 2012). This would be confusing to a teacher who does not understand this illness, when a child periodically feels worse and has more symptoms than less. Other difficulties can occur when children need to take medication frequently, and often during the school day; the profound fatigue of the illness alone and while healing; and the demand on a child's time to make long trips to see a Lyme Literate Medical Doctor. Another problem is that very sick kids do not always look sick. How ill children are, is not reflected in what teachers and other school professionals see when they look at them (Berenbaum, 2002).

Some adjustments the school can offer to help functional impairments include but are not limited to considering:

- The length of the school day
- The time school begins and ends
- Length of homework assignments
- Length and location of tests
- Physical education requirements

In the school-age population, individuals found to have a disability that substantially limits one or more major life activities, but is not significant enough to qualify as a student with a disability, may qualify for a Section 504 plan. The U.S. Department of Education allows a 504 plan to be in effect under the Americans with Disabilities Act Amendments Act (ADAAA) of 2008 (ADAAA, 2008). A letter from a child's treating physician should be substantial for a 504 meeting to convene regarding a child's needs. If a 504 plan does not adequately meet a child's needs for accommodations, a child with a health problem may receive services under Other Health Impaired (OHI), if they meet the criteria for disability. This would occur after an IEP (Individual Education Plan) meeting determined a child to fall under this category. An IEP meeting occurs when school professionals relevant to the child's education such as the child's teacher(s), school psychologist, principal, parent, and any other person in direct contact with the child (e.g. social worker) meet and discuss findings after a school psychologist has assessed the child. Often, a neuropsychological evaluation is done to assess if a child meets the criteria for a learning disability. Behavioral assessments are also used in appropriate situations. Each assessment is tailored to the child's difficulties. In this meeting, if a child meets the criteria for special education an IEP is created. Accommodations for the child will be written into the plan, and can provide resources that are not covered under a 504 plan (Berenbaum, 2002). Accommodations, which may follow a neuropsychological evaluation, take into consideration any specific learning problems and needs and may include:

- Unlimited time allotted for testing- Some children with Lyme have difficulty with the processing speed of information. When a child is given an extended time to take tests, it gives them enough time to think.

- Separate testing location- This is helpful for children who are easily distracted, and has difficulty with focusing and concentrating.
- Tests read to students- This is an option for students who have learning problems, where their auditory learning is less impaired than their visual learning.
- Excused from a percentage of homework- This is beneficial for students with profound fatigue who had difficulty getting through the school day. It makes it easier for them to have less work at home.
- Decreased choices on multiple question tests and homework. Elimination of one or more answers can be helpful.
- Shortened versions of tests

These are just some ways a child can be accommodated (Berenbaum, 2002).

Attentional problems and cognitive problems are common amongst children with Lyme, as mentioned earlier. One problem children may face is retaining new information. Lyme can also affect expressive and receptive language, visual-spatial processing, abstract reasoning, and processing speed. Lyme can not only affect any part of the body, but it can affect any cognitive process (Berenbaum, 2003).

These children are often (or appear to be) easily distracted, have poor concentration, may appear scattered, and display any symptom of Attention Deficit Disorder (ADD). If the child was diagnosed with ADD before Lyme disease, then the ADD symptoms are often exaggerated by the illness (Berenbaum, 2002; Healy, 2000).

## Educating Schools

Greenwich Public Schools in Connecticut is located in one of the most Lyme endemic areas of the country (CDC, 2012; Lang & Liegner, 2004) Due to the huge impact Lyme disease has on families, a previous superintendent of this district, Dr. Melendez, put together a seminar with a panel of doctors and advocates from across the country, to help address the problem. This evening event was videotaped and has been distributed to other school districts around the country. Any school district can request it in video or DVD along with a curriculum that has been created for grades K-3, 6, and 9 through Lyme Research Alliance (Lang & Liegner, 2004; Lyme Research Alliance, 2013). In other areas where Lyme is endemic, like New Jersey, the Lyme population amongst students can reach as high as 30%, during which time they close school (Lang & Liegner, 2004).

School-aged children usually spend more awake time at school than they do at home with their parents. It is vital that school teachers, nurses, administrators, psychologists, social workers, and any other school professionals working with children are educated on Lyme disease. If school professionals could come together to work as a team, it would greatly benefit all children suffering from Lyme. Stress from school can worsen the symptoms of Lyme (Lang & Liegner, 2004). School psychologists may be ideal professionals to be aware of the complications of Lyme Disease because so many of the symptoms interfere with the child's ability to benefit from educational experiences. However, it is not known how familiar school psychologists or other school based professionals are with Lyme Disease and its complications.

## Controversies

There are some controversies surrounding Lyme disease. There are essentially two camps with positions about some political issues around this disease. On one side you find the Lyme Literate Medical Doctors (LLMDs) who usually focus solely on treating Lyme disease patients. The other side consists of typically infectious disease doctors who treat people with a variety of infectious diseases. There are some infectious disease medical doctors who believe that a short course of antibiotics (often 14-21 days) will cure all Lyme disease. They believe that if problems persist after antibiotic therapy, the patient is then suffering from a different condition called "Post-Lyme Disease Syndrome". Their claim is that despite persisting symptoms, infection does not persist and has been treated (Brody, 2013; Wright et al., 2012). LLMDs believe that a short course of antibiotics can eradicate Lyme when it is caught early, as do infectious disease doctors. But, in cases where patients with Lyme disease have gone undiagnosed for longer periods of time, they believe in prescribing longer term antibiotics. Some Lyme sufferers improve with long-term antibiotic therapy, or IV antibiotic therapy (Brody, 2013). Research has shown that Lyme disease can persist in those that have received antibiotic therapy and are still symptomatic as spirochetes are found in the blood and tissues of their bodies (Grier, 1997). Yet, there is still a difference of opinion between these two groups of physicians.

## Statement of the Problem

There is a lack of education on the subject of Lyme disease in schools. The purpose of this thesis was to create a compilation of materials that can be provided to school districts for the use of providing information for school professionals, on the subject of Lyme disease.

## CHAPTER III

### METHODS

The purpose of this study was to provide comprehensive materials for schools on the subject of Lyme Disease. There is a lack of awareness and education on the subject of Lyme Disease. A power point presentation was created, for school professionals, to highlight important aspects of Lyme disease. It provides basic information on the disease, prevalence, incidence in children, prevention, symptoms, and ways to identify certain symptoms that occur during the school day. Along with the power point presentation, a packet of handouts and resources was also developed.

The powerpoint presentation was submitted to three people who specialize in the area of Lyme disease. Linda Purdy is the President of the Michigan Lyme Disease Association (MLDA), also manages the Michigan Lyme Disease Support Group on Yahoo. She reviewed the presentation and information to provide feedback on her thoughts regarding accuracy, thoroughness, and appropriate amount of information presented for the purpose of this study. As well, Brendan Fillar, the co-owner of Lyme and Cancer Services, reviewed the powerpoint presentation and provided his feedback. Dr. Clifford Fetters, D.O. in Carmel, Indiana, provided his feedback after reviewing the power point presentation. Dr. Fetters treats over 70 Lyme disease patients.

## CHAPTER IV

### RESULTS

A package of materials on the subject of Lyme disease was created to provide to school systems, so they can properly educate their school professionals on a disease which affects children. These materials consisted of a power point presentation that addresses the main points of the disease that is relevant in learning about Lyme disease. A list of resources is also provided, which includes reputable websites with up-to-date information on Lyme disease, organizations that pertain to Lyme disease, a documentary on Lyme, and where to find lists of treatment guidelines, comprehensive Lyme symptom lists, and Lyme disease checklists. Along with this information, a short check list was included that can be used to gather information that would be helpful in determining if a child or adult has symptoms that could be due to Lyme disease.

The power point presentation was reviewed by Linda Purdy, president of the MLDA to gain her perspective and feedback on the accuracy, thoroughness, and appropriate amount of information provided. Linda commented, "I think you did a good job, especially having to keep it brief"; she thought it was properly put together for a concise powerpoint presentation. Linda offered a couple useful pieces of information to include in the powerpoint; her feedback was incorporated. She suggested I include that it may take several tries to remove a tick, while pulling it out with tweezers. She also suggested I include that after a tick bite, symptoms may not develop for up to 30 days. She said it was important so people didn't think they were safe after two weeks post bite. Linda found the information provided to be accurate.

Brendan Fillar commented that the power point presentation "looks great". He found the information to be accurate and thorough. His one piece of advice was to consider including

information on co-infections that can be transmitted by an infected tick, along with Lyme disease. This suggestion was not incorporated to ensure adequate coverage of Lyme disease.

Dr. Clifford Fetters, D.O., commented, "It looks like an excellent power point presentation." He found the information to be both accurate and thorough.

The appendices include handouts on Lyme disease. Appendix A includes a list of resources where more information on Lyme disease can be located. Handouts from the powerpoint presentation are listed in Appendix B. Appendix C is comprised of three different materials from Lyme Research Alliance. The first is a letter of referral for a school professional to fill out if they suspect a student has Lyme disease. The second handout is a notification of field trip letter for parents. It highlights the risk of tick bites and what to look out for in case a student is bit and developed Lyme disease. Thirdly, a Lyme disease checklist with a list of some of the common symptoms of Lyme is provided.

## CHAPTER V

### DISCUSSION

Information on Lyme disease has been compiled to create a group of materials that would allow a school district to educate any school professionals on relevant information about Lyme disease. Children make up a large percentage of the people who are diagnosed with Lyme disease (Lyme Disease Association, 2012). A child with Lyme disease may present with behaviors in the school environment that require interventions. As well, a child may present with problems that are indicative of Lyme disease, when they have yet to be diagnosed. Lyme disease is a growing epidemic, and is found in every state of the U.S., therefore, it is important for schools to have accurate knowledge about a disease that is affecting children. The materials provided included a powerpoint presentation that addresses the major aspects of the disease including prevention, prevalence, symptoms seen in the school environment, along with information for parents regarding how to safely and properly remove an embedded tick. It is important that if school personnel find an embedded tick on a child, that they notify the parents so the parents can remove it as soon as possible to reduce the risk of infection. It would also benefit schools to mention the risk of tick bites in field trip consent letters including providing general information on Lyme disease.

The powerpoint presentation was reviewed by Linda Purdy, president of the MLDA, Brendan Fillar, president of Lyme and Cancer Services, and Dr. Clifford Fetters of Health and Wellness of Carmel. All parties reported that the information provided was accurate and well done.

### Limitations of Study

A limitation of this thesis is that this powerpoint presentation and compilation of materials has not been administered to any schools. Without administration, or presentations, there is a lack of feedback from school professionals regarding what they have or have not learned from the information provided. Therefore, we do not know the effectiveness of the materials created.

### Implications for School Psychology

Having these materials would allow a school psychologist to provide in-services to teachers or other school professionals. It would also allow a school psychologist to gain feedback on this material to determine if it is helpful and informative. Also, with access to this information, a school psychologist could identify what behaviors a child with Lyme disease may have due to the disease, as opposed to general defiant behavior, learning difficulties, etc. Understanding why a child is exerting certain behaviors can impact what can be done to help him/her in the school environment.

### Conclusion

Together, the power point presentation, along with a check list of Lyme disease symptoms, and a list of resources where more information on Lyme can be found, comprise a set of materials useful for school education. This information could be used by a school district to create an in-service for school professionals on Lyme disease. It would be a beginning to the creation of a school-wide project to educate children based on a curriculum such as the one developed in Greenwich, CT. In Greenwich, there is a curriculum implemented into the school districts during grades K-3, 6, and 9. At each level, information is provided that is age

appropriate. This curriculum was not used in this thesis as it was developed for children and the materials provided in this thesis project are for school professionals. There are many benefits to educating the students from a young age, and continuing that education throughout their school aged years. If students are educated on Lyme disease, they can help prevent the attachment of ticks, and be more aware of tick bites by doing self tick checks after being outdoors and while in the shower. A school or district-wide program may benefit both the students and school personnel. This project could provide the beginning steps of a much larger project that would benefit any school district.

## APPENDICES

## APPENDIX A

### RESOURCES ON LYME DISEASE

#### Websites

[www.ILADS.com](http://www.ILADS.com)

[www.lymediseaseassociation.org](http://www.lymediseaseassociation.org)

[www.canlyme.com](http://www.canlyme.com)

[www.clda.com](http://www.clda.com)

[www.lymenet.org](http://www.lymenet.org)

[www.Igenex.com](http://www.Igenex.com)

[www.underourskin.com](http://www.underourskin.com)

#### Organizations

Center for Disease Control

International Lyme Disease Association

Children's Lyme Disease Association

Lyme Disease Association

#### Media

Under Our Skin, Open Eye Productions, documentary

#### Other Resources

Treatment guidelines by Dr. Joseph Burrascano

[http://www.ilads.org/lyme\\_disease/B\\_guidelines\\_12\\_17\\_08.pdf](http://www.ilads.org/lyme_disease/B_guidelines_12_17_08.pdf)

Symptom checklist by Dr. Joseph Burrascano

[http://www.lymediseaseassociation.net/images/NewDirectory/Resources/DrB\\_SymptomList2005Pdf.pdf](http://www.lymediseaseassociation.net/images/NewDirectory/Resources/DrB_SymptomList2005Pdf.pdf)

List of symptoms by Lyme Research Alliance

<http://www.lymeresearchalliance.org/signs-symptom-list.html>

APPENDIX B

POWERPOINT

The Effects of Lyme Disease on School Children  
Enhancing the Knowledge Base of School Professionals

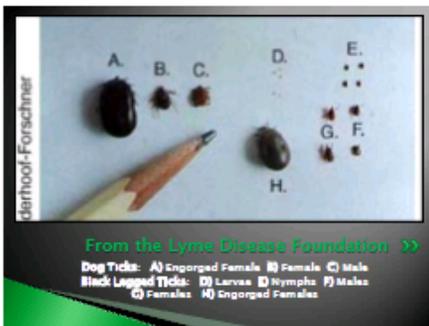


What is Lyme Disease?

- A bacteria called Borrelia Burgdorferi
- A spiral shape that allows it to burrow more easily into deeper tissues and organs
- Most common vector-borne disease in the U.S.
  - A vector-borne disease is an infectious disease spread through blood sucking agents such as biting flies, mosquitoes and ticks

Transmission

- Lyme is primarily spread through the bite of infected ticks
- Lyme is also passed in utero or through breast milk
- Lyme disease is spread via ticks attached to mice, deer, migrating birds and other small animals
  - This is how they have moved out of wooded areas into suburban backyards



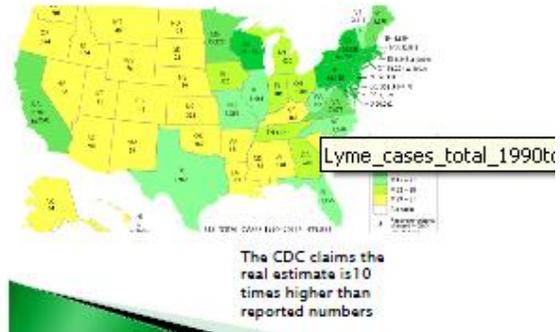
Myths

- Lyme Disease does not exist in all states.
- A bulls-eye rash is always present when you contract Lyme disease

Myth Busters

- Lyme Disease has been reported in all 50 states.
- A bulls-eye rash is positive identification of a Lyme infection, but is not always present

Myth	Myth Busters
<ul style="list-style-type: none"> <li>If you are bitten by a tick, you will know it, and you will see the tick.</li> </ul>	<ul style="list-style-type: none"> <li>Ticks can be as small as a poppy seed or grain of pepper. They easily go unseen.</li> </ul>
<ul style="list-style-type: none"> <li>Lyme is a rare disease.</li> </ul>	<ul style="list-style-type: none"> <li>Lyme disease is growing and has become an epidemic.</li> </ul>



## Prevalence

- According to the Center for Disease Control and Prevention (CDC), 300,000 new cases of Lyme are reported each year.
- Lyme is an epidemic and pandemic, occurring in all 50 states and in over 80 countries.
- It is growing at a rate 4 times faster than HIV/AIDS (CDC)

## Prevalence in Children

- Children under the age of 12, comprise 50% of all Lyme cases (Lang & Liegner, 2004)

### • On the Contrary

- Children between the ages of 5-19 make up 25% of all Lyme cases, and are at the highest risk for Lyme infection (CDC).
  - This is 3 times higher than all other age groups (2012)



## Prevention

- Wear insect repellent when planning on being outdoors, especially near areas with tall grass, brush, trees, etc.
  - DEET is recommended to repel ticks.
- Wear light colored clothing.
- Wearing long pants and sleeves helps keep ticks off the body. Tuck long pants into socks.
- Put clothes into the dryer before washing them to kill any ticks on the clothing.
- Do Tick Checks after being outdoors.
  - Behind knees, in groin area, armpits, and scalp
  - Showering to wash off any unattached ticks

## Information for Parents

- Tick Removal
  - There is only one proper way to remove an embedded tick.
  - Tweezers
    - Use tweezers to grab the body of the tick as close to the skin as possible.
    - Pull straight out. It may take several tries.
- The tick can be saved for testing if kept alive.
  - Any other methods of removal will increase the chance that the tick will inject the body with infectious fluids.





### Common Symptoms

- ▶ Within hours to up to 30 days after a tick bite one might present with:
  - Fever
  - Aches and pains
  - Headache
  - Bulls-eye or other rash
  - Sore throat
  - Fatigue
  - Flu-like symptoms

When Lyme Disease is not caught early and has not been treated... >>

Chronic Lyme Disease can occur, where symptoms spread and become more serious.

### Chronic Lyme Symptoms

*Noticed in the School Environment*

- ▶ Developmental Delay
- ▶ Learning Disabilities
- ▶ Poor short-term memory
- ▶ Poor Concentration
- ▶ Inability to sustain attention-ADD/ADHD
- ▶ Outbursts, Mood swings
- ▶ Depression/Anxiety
- ▶ Trouble thinking and expressing thoughts
- ▶ Confusion/Brain Fog

Cognitive Changes

### Chronic Lyme Disease Symptoms

*Noticed in the School Environment*

- ▶ Withdrawal from peers/loss of friendships
- ▶ Decline in Academics
- ▶ Poor attendance/Tardiness
- ▶ Gastrointestinal symptoms
- ▶ Sensitivity to light and sound
- ▶ Poor sleep
- ▶ Behavioral problems
- ▶ Severe pain, profound fatigue
- ▶ Muscle twitching

Other Noticeable Symptoms



APPENDIX C

HANDOUTS ON LYME DISEASE

LYME DISEASE

**Criteria for Student Referral to School Nurse/ School  
Teacher/Psychologist/Social Worker**

Lyme disease can affect all aspects of a child's life: physical, social and academic.

Symptoms can range from subtle to severe and can come and go which may result in inconsistent school performance. The signs listed below, while not all-inclusive, are the ones that would be seen most frequently in the school environment. It is important to realize that the symptoms of Lyme disease can be intermittent as the symptoms often cycle. Any student identified as experiencing a combination of the following for over a one-month period should be referred to the school nurse. Of course, this one-month period is only meant as a guideline. Open communication with parents and school nurse is always recommended.

**Academic :**

- Decline/inconsistent school performance
- Significant variance in standardized testing
- Confusion, memory/concentration problems

**Date(s) observed**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Social:**

- Irritability/mood swings
- Overemotional reactions
- Anxiety
- Apathy/withdrawal

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Physical:**

- Fatigue
- Headaches
- Stomachaches
- Joint pain/Muscle pain
- Vision problems/eye twitching
- Hearing problems
- Loss of coordination/clumsiness

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Lyme Research Alliance, Inc®

2001 West Main Street, Suite 280, Stamford, CT 06902

[www.LymeResearchAlliance.org](http://www.LymeResearchAlliance.org)

## Notification of Field Trip

### TICK ALERT:

Your child is scheduled to take part in an outdoor activity in an area that ticks may inhabit.

While we will take every precaution to prevent unnecessary exposure, a thorough tick check of your child upon return home would be prudent. Below are suggestions from Lyme Research Alliance Inc. on how to protect your child from tick bites and what you should do if your child is bitten.

### REDUCE CHANCES OF A TICK BITE:

Avoid tick-infested areas, such as leaf litter under trees. Avoid brushing against long grasses on edges of paths. Wear light-colored long pants and long sleeves so you can easily see any ticks. Tuck shirt into pants and tuck pants into socks.

Use EPA-approved tick repellents. Those containing Deet and permethrin are most effective against ticks. Follow product directions.

Wash off repellent after you return. Do a thorough tick check upon returning inside.

Ticks, especially nymphal ticks, are tiny.

### WHAT TO DO IF BITTEN:

Using fine-point tweezers, grasp the tick as close to the skin as possible. Pull the tick straight out with steady, even pressure.

Place the tick in a small plastic bag with blades of grass, leaf, or moist (not wet) piece of tissue.

Note the person's name, date, site of bite and estimated duration of attachment.

Have the tick identified & tested by a lab, health department or veterinarian. Wash your hands, disinfect the tweezers & bite site.

Educate yourself about tick-borne diseases and consult a doctor to see if treatment is warranted. Visit [www.lymediseaseassociation.org](http://www.lymediseaseassociation.org) for more information.

Date & Location of Trip \_\_\_\_\_  
Teachers Name \_\_\_\_\_



**Lyme Disease Checklist**

Name: \_\_\_\_\_ Date prepared: \_\_\_\_\_

The following symptoms may fluctuate in cycles:

**Tick Exposure:**

\_\_\_\_\_ Known Tick bite

**Academic:**

\_\_\_\_\_ Work or schoolwork decline  
 \_\_\_\_\_ Significant variance in work performance or Standardized test Results

**Psychological:**

\_\_\_\_\_ Anxiety  
 \_\_\_\_\_ Mood swings, Irritability  
 \_\_\_\_\_ Unusual depression, Withdrawal  
 \_\_\_\_\_ Overemotional reactions (inappropriate)  
 \_\_\_\_\_ Violent outbursts

**General:**

\_\_\_\_\_ Headaches  
 \_\_\_\_\_ Fatigue  
 \_\_\_\_\_ Sore throat  
 \_\_\_\_\_ Tingling in extremities  
 \_\_\_\_\_ Twitching or paralysis of facial muscles  
 \_\_\_\_\_ Vision (double, blurry, light sensitivity)  
 \_\_\_\_\_ Ears (ringing, loss of, sensitivity to noise)  
 \_\_\_\_\_ Joint pain, swelling or stiffness  
 \_\_\_\_\_ Muscle pain, cramping or weakness  
 \_\_\_\_\_ Stomachaches or digestive problems  
 \_\_\_\_\_ Rash

**Respiratory:**

\_\_\_\_\_ Shortness of breath  
 \_\_\_\_\_ Chest pain, Heart palpitations or Heart block

**Central Nervous:**

\_\_\_\_\_ Tremors or unexplained shaking  
 \_\_\_\_\_ Clumsiness, Poor Balance, Loss of Coordination  
 \_\_\_\_\_ Dizziness  
 \_\_\_\_\_ Attention/Concentration problems  
 \_\_\_\_\_ Hyperactivity  
 \_\_\_\_\_ Memory loss  
 \_\_\_\_\_ Confusion, Brain fog  
 \_\_\_\_\_ Forgetfulness  
 \_\_\_\_\_ Speech difficulty (slow, slurring)  
 \_\_\_\_\_ Auditory/Visual processing problems  
 \_\_\_\_\_ Word retrieval problems

While this list is not all-inclusive for Lyme disease, if a person experiences a combination of these, it may be an indication that the individual should be screened for Lyme disease and/or other tick borne illness.

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