LDA Analysis of Lyme Disease Data by Age from 2001-2017

Lyme Disease Association, Inc.
Analysis of Lyme Disease Data by Age from 2001-2017

Source Data: CDC Lyme Disease Reported Case Numbers 2001-2017 by Age
Ages 0-19 at High Risk

Adults 20-90+ years
272,872
71%

Children 0-19 years
110,974
29%

Source figures accessed 9/15/19 from https://www.cdc.gov/lyme/stats/graphs.html
Total case numbers: 383,846
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Click here for pdf of pie graph

Brian Dashore Guest Blog

May Awareness LDA Guest Blogger
Brian Dashore is a 17-year-old teen who has had Lyme Disease, Mold Biotoxin illness, and other co-infections. He has been undergoing treatment for eight years with multiple world-renowned doctors. Brian is the son of Jodie Dashore who is a well-known doctor in this field. He recently established a website called teenlymehub.com with a Facebook group. He will be talking about the educational aspects of a child with Lyme Disease.

How My Differing Childhood Experiences Impacted My Educational Life

I clearly recall running at baseball practice when my left leg started to drag. I was only 6 years old,
and I just kept trying to run. A burning sensation ran up to my pelvis. My coach thought I pulled a muscle and sent me home.

When I arrived home, my mom, a neurologist and naturopathic doctor, evaluated me. She couldn’t find a reason for the pain and near paralysis of my leg. We traveled to Boston to see her good friend, an orthopedic surgeon at Harvard. After a battery of tests including nuclear full body bone scans and 20 tubes of blood, they put me in a wheelchair.

The results were inconclusive.

We saw nineteen specialists before receiving a referral to a pediatric Lyme-literate specialist. I was diagnosed with Lyme disease, Bartonella, and 11 coinfections.

By this time, I had also developed several other symptoms. My face began to grimace and twitch. It felt like bugs were crawling under my skin and my brain was shivering. I also gradually grew mentally and physically weaker. I frequently lost my balance and had an assortment of cognitive issues. My anxiety increased and sleep brought on night terrors.

The pain and dragging of my leg meant that I was still in the wheelchair when I returned to school. My immune system was also weak and reactionary, so I also had to wear a mask in the hallways at school.

These presented their own world of challenges. I frequently faced bullying on the playground. The school bus rides were full of bigoted, discriminatory, and snide remarks. My guidance counselor suggested sharing my condition with my classmates might help.

I stood in front of my fourth-grade class and spoke about my condition. It was a turning point for my classmates and me. They shared that they were afraid to “catch” my motor tics, blinking eyes, head nodding, vocalizations, limp, back pain,
and limited range of motion in my head and neck.

Speaking in front of my class, opened the discussion to understanding. I think for fourth graders is a huge milestone, and it seemed to help. Some of my classmates started steering my wheelchair for me. Others carried my bag. A few even came over to my house for playdates. That moment also taught me that I can’t rely on others to advocate for me. I need to be able to bring change to my own world.

My physical limitations extended into academic challenges too. When my treatment began, the school provided academic accommodations. I struggled with handwriting, math word problem, focus, and concentration. Soon enough it felt like the fog lifted. I was able to understand and grasp things that had been difficult. Many of my physical issues were also diminishing and vanishing.

As I reflect back, it’s been a long journey. There is still more work ahead, but I have goals and feel I can achieve them. I’ve had the good fortune of growing up around my mom’s practice and the work of her mentors. My involvement in the Lyme community also opened doors for me. I’ve spoken alongside Congressman Chris Smith, Dr. Robert Bransfield, and Mrs. Smith.

I’m entering my senior year at a rigorous pre-med integrated health and science high school in the fall. So, I’ll spend my summer working on my goals. I’m sharing my story at AutismOne in Chicago. I need to decide where I will apply to medical school. Helping others is important to me, so I’m also active in my online support group, TeenLymeHub which is featured on my website teenlymehub.com.
Current research indicates that the longer a tick is attached, the greater the risk of infection. Lyme disease bacteria can enter the central nervous system within 24 hours after a tick bite. Failure of parents and teachers to recognize Lyme disease early in its course can result in a child developing a chronic difficult to treat infection in the brain, eyes, joints, heart and elsewhere in the body. Free (shipping costs for large quantities)
Video and Video Game for Kids!

Watch Tick Video, Then Play Tick Tackler Video Game

Acting under the auspices of an Environmental Protection Agency grant, UMDNJ compiled an expert team to develop the video, TickLES (Tick Learning and Education for Schools) and the Tick Tackler Video Game and make it kid friendly and fun! LDA was a project collaborator and is responsible for hosting the TickLES video and Tick Tackler Game on its website for use by the public, for free.

The Lyme Disease Association (LDA) and the Game is not affiliated with Tick Tackler, LLC.

TickLES Video

Video Game for Kids! Click Here
Free & Fun Video/PowerPoints for Kids

The Lyme Disease Association (LDA) and the University of Medicine & Dentistry of NJ School of Public Health partnered to create a video, TickLES (Tick Learning and Education for Schools) for students in grades 4-8. Under an Environmental Protection Agency grant, UMDNJ compiled an expert team to develop the material and make it kid friendly and fun! LDA, a project collaborator, is hosting the video on its site for free use by the public. Click here for LDA Press Release

Tickles teach children prevention measures, what to do when bitten by a tick, how to recognize a tick attachment (bite) and the symptoms of Lyme disease. Since children ages 5-14 are at the greatest risk of acquiring Lyme disease, the LDA feels it is important to educate them on prevention and disease recognition.

How A Tick Can Make You Sick, a PowerPoint, was developed solely by LDA after working for decades with schools on Lyme and other tick-borne diseases. Input was sought from doctors, a family psychotherapist, a former special services director, a microbiologist, teachers, Lyme group leaders, and kids. No
medical advice is given or intended.

Everything is provided for general informational use only and specific questions need to be referred to tick experts and health care providers.

How A Tick Can Make You Sick PowerPoint (Click Here For Powerpoint)

TickLES Video
The Effects of Lyme Disease on Students, Schools and School Policy

While it comes as no surprise that the numbers of classified students are increasing, it may surprise some to know that Lyme disease may be causing many of the learning problems experienced by students in Lyme-endemic areas. New Jersey ranks fourth in the nation in Lyme cases.

Many students with Lyme are classified, receiving accommodations and support in an individualized education program or 504 plan. A 1992 New Jersey law requires school districts to annually educate any teaching staff member who instructs students with Lyme disease.

Lyme is the most prevalent vector borne disease in the United States, and case numbers have increased by 40 percent in 2002. Only 10 percent of cases are reported, which translates to about 240,000 new cases in 2002. Unfortunately, children are at the greatest risk of acquiring the disease, and 10 to 15 percent of Lyme cases become chronic.

In 1992, while I was a Wall Township Board of Education member, Congressman Christopher H. Smith invited me to Washington, D.C., where I presented a study to the Centers for Disease Control and the National Institutes of Health on the impact of Lyme disease on school children in nine New Jersey districts.

Of the 64 students studied, the CDC found that the median duration of
Lyme disease was 363 days; the mean number of school days missed due to illness was 103; the median duration of home instruction was 98 days; more than one-third of families of affected children had three or more members at some time diagnosed with Lyme disease, including 40 percent of the mothers; 78 percent of parents stated their children experienced a fall in grade point average during the time of illness; and 79 percent experienced a decrease in friends.

A CDC study quote sums up the magnitude of the problem: “Perhaps the greatest costs incurred by the study children were the social costs of the illness and its treatment. Schooling and extracurricular learning activities were seriously interrupted for most children. Often, children spent large blocks of time as semi-invalids, isolated from social groups and missing out on cultural, sports and social activities. School performance of nearly all children fell, sometimes drastically, and in several instances was said to interfere with selection by colleges and universities.”

Lyme can affect all the systems of the body and its signs and symptoms are varied. Often children exhibit problems associated with Lyme, especially behavioral and mood changes, that go unrecognized by districts. At times, children may be improperly classified, labeled neurologically impaired or emotionally disturbed when perhaps a classification including “other health impaired” might be more appropriate to address the medical problems triggering the neurologic and/or psychiatric problems that stem from Lyme.

Children may be identified with attention deficit disorder, medicated for those symptoms, and no cause is ever sought. According to Dr. Brian Fallon, Columbia University associate professor of psychiatry and director of the Lyme Disease Program of the New York Psychiatric Institute, a child who is inattentive and fatigued often should probably be evaluated for Lyme disease.

Another difficult diagnostic situation arises when a child has attention deficit hyperactivity disorder, and then develops Lyme disease. This patient continues to have symptoms associated with hyperactivity, whether behavioral, fidgeting, or interrupting, and now may additionally be
inattentive and fatigued due to Lyme.

Districts need to carefully evaluate any child with a history of Lyme disease who is experiencing neurologic, psychiatric, and attention deficit problems to ensure the problems are not organically produced by Lyme, since the bacteria causing the disease can enter the central nervous system less than a day after a tick bite. Additionally, the role of co-infections, diseases transmitted by the same ticks, needs to be examined.

Recurrent short-term memory, concentration and recall problems, mental confusion, and exhibition of dyslexic type symptoms are not uncommon and interfere with the learning process. One Columbia University study documents IQ improvement of 22 points in a 16-year-old after intravenous treatment for Lyme disease.

Fluctuations in, and the variety of, symptoms present another problem for the school and often lead to a misunderstanding about a child’s condition. Lyme symptoms can vary from day to day, hour to hour. Serious sleep disturbances may cause a child to oversleep in the morning because of difficulty falling asleep at night. Executive functioning may be impaired and the child may have difficulty organizing his/ her day or life. Couple that with forgetting books and homework assignments, especially in a middle or high school, and questions about the validity of the child’s illness surface.

Suicide can occur in children with Lyme. In one New Jersey case, the child felt that no one understood her Lyme disease problems. In another, a young man stopped his medications after a psychiatrist told him he did not have Lyme, it was all in his head. He could not bear the pain from the disease. Lyme disease pain has been described in studies as equivalent to that of congestive heart failure.

A district needs to understand its legal obligations in educating a child with Lyme disease. It also needs to recognize that, with a disease of this complexity, it must work closely with the parents and the student who are sometimes the only ones who understand what the student is capable of in a particular situation at a particular period of time.
Information from Lyme support groups can be very helpful in this process.

School policies often forbid attendance at activities after or during an absence, but the situation involving a child with a chronic condition like Lyme disease does not fit into any existing paradigm. Board policies often need to be modified for a student with Lyme disease, since a child may be out of school for extended periods of time, although he or she may be capable of attending a particular event. Absences of months to years often make a student a social outcast and recluse. Allowing this minimal school interaction, and not questioning the child’s, parent’s or doctor’s honest assessment of the illness can go a long way toward preventing the development of school phobia, thus easing a child’s transition back to school when he or she is well enough to attend.

Boards also need to examine policies relating to homework and class trips. Policies generally set a length of absence required before homework is sent home. Because of the unpredictability of symptoms, and frequent and sometimes short absences of students with Lyme disease, homework needs to be supplied without any waiting period. Outdoor class trip policies and procedures should also include information about the dangers of Lyme disease, thus protecting the staff and children from unnecessary exposure to the disease and the district from unnecessary expense and/or litigation if these elements are not in place.

Lyme presents a myriad of problems for both patient and district, not the least of which is the variable teachable moments of a student with Lyme disease. Proactive intervention by a school district and cooperation with a financially, emotionally, and medically burdened family can ensure student success and often lead to solutions, which are far less costly overall for the student and for the school district.

Patricia V. Smith is president of the Lyme Disease Association, Inc. and vice president of political affairs for the International Lyme & Associated Diseases Society. She is a former president of the Wall Township Board of Education and a former officer for the Monmouth County School Boards Association. Ms. Smith can be reached at Lymeliter@aol.com.
You Can Make A Difference to a Child by Reducing Risk of Lyme Disease – NASN Sch Nurse

Featured in the updated 2019 The ABC’s of Lyme Disease –

You Can Make A Difference to a Child by Reducing Risk of Lyme Disease
Network to Reduce Lyme Disease in School-Aged Children, Washington, DC

Click here for link to full article


Abstract: Early detection is critical since you are on the front lines when educating school staff and students. You, as the school nurse, can make a huge difference in a child’s life by providing guidance on Lyme disease prevention, detection, and treatment to your school staff, as well as the parents of the community

CDC Early Study Pinpoints
Problems in School Children with Lyme

Background of 1992 CDC school study of children on home instruction
by Pat Smith, published in the Lyme Times, Summer 2006 (used with permission)

In March 1992, LDA president Pat Smith was invited to the DC office of Congressman Christopher Smith (NJ) to present to officials from the National Institutes of Health and the Centers for Disease Control and Prevention (CDC) information on how Lyme disease impacts school districts. These officials included Duane Gubler, ScD, CDC, Director, Division of Infectious Diseases and David Dennis, MD, MPH, Lyme Disease Program Director. Pat, at the time a Wall Township (NJ) school board member, presented a compilation of data gathered from nine school districts in NJ. The data included children on home instruction, teachers with Lyme, home instruction costs related to Lyme disease, and costs of treatment (actual cost, insurance payment, and family cost). As a result of her presentation, the CDC visited NJ and selected five of the nine districts for an intensive study, beginning with CDC meetings in Pat’s district which at the time had 55 Lyme cases. Pat helped the CDC develop some of the study parameters and aided in district cooperation. The draft CDC school district study was completed but never published despite intense efforts on Pat’s part to make that happen. Study information however, was presented to a packed house in an October 1992 Wall Township Congressional meeting on Lyme disease hosted by Congressman Smith where Mr. Gubler, Dr. Dennis and Pat all spoke. The draft CDC school district study follows in its entirely with the exception of the eleven data tables which were eliminated due to space constraints.

INTRODUCTION
The following brief narrative summarizes the descriptive findings of a recent Centers for Disease Control (CDC) and New Jersey State Department of Health field study of the social and economic impact of Lyme disease in school children living in a five-township area of Monmouth and Ocean counties, New Jersey. The analysis of data is restricted to cases (students in grades K-12 in the five-township area who, because of illness diagnosed as Lyme disease, required home instruction in the school years 1990-91 and/or 1991-92). Data on controls are not included because interviews with controls are incomplete. The data provided in this report are derived from interviews with parents of 65 case-patients from 54 households. The background of the investigation, the methods employed (including a copy of the questionnaire), and preliminary summary statistics are included in a report from Dr. Susan E. Lance to CDC Epidemiology Program Office, with copies to the New Jersey State Department of Health, dated August 4, 1992.

Link to full study with tables

Link to Lyme Times article on study

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**Lyme Prevention Powerpoint for Kids**

**Features:**

- Free
- Can run from the Internet
- Can download and print the presentations
- Audio pronunciation guide
- Pre- and Post-Tests included
How A Tick Can Make You Sick

Dear Educator, Camp Counselor, and Others who work with students/children:

One of the goals of the Lyme Disease Association (LDA)—an all-volunteer, national organization—is to increase education about tick-borne diseases. The LDA already has educated millions of people to date, but reported cases of Lyme disease continue to rise at an alarming rate—by 39 percent from 2006 to 2007. The tool we have provided here, “How A Tick Can Make You Sick,” can be used successfully with audiences from middle school students through adults. A few slides are a bit more complex, e.g., slides on co-infections, and those can be glossed over by the presenter for younger students.

The Lyme Disease Association has developed this slide show after almost 20 years working in schools with teachers and with students on Lyme and other tick-borne diseases. The LDA has asked doctors, a family psychotherapist, a school district special services director (retired), a microbiologist, a teacher, Lyme disease group leaders, and kids to review the presentation. We have tweaked the content provided here to make it more interesting for students and to be Web friendly.

Online Modules:

- Module 1: What is Lyme disease
- Module 2: Tick-er Tape Parade: What are ticks and what do they look like?
- Module 3: Keeping ticks at bay when you go out to play
- Module 4: Testing and treatment for Lyme disease
- Pronunciation Guide

Printable Version of Each Module:

- Adobe Acrobat PDF Module 1: What is Lyme disease
- Adobe Acrobat PDF Module 2: Tick-er Tape Parade: What are ticks and what do they look like?
- Adobe Acrobat PDF Module 3: Keeping ticks at bay when you go out to play
- Adobe Acrobat PDF Module 4: Testing and treatment for Lyme disease

Knowledge Assessments:

- Pre-Test
- Post-Test A
- Post-Test B
- Post-Test C
- Answer Key (for all tests in one document)

Resources:

LDA Maps Lyme Across the USA – View Reported Case Numbers with a click!

Individual maps from 1990 through 2010 and total case number map 1990-2010 including state reporting criteria changes. Click on individual states for a pop up case number table and an incidence map. All have printer-friendly versions. Free
AVAILABLE NOW! Time for Lyme Curriculum for Schools

In a cooperative effort between Connecticut-based Time for Lyme, Inc. (TFL) [an LDA affiliate] and Connecticut school administrators, TFL created a tick-borne diseases curriculum with age-appropriate goals, activities, and measurable guidelines—one that includes tick awareness, prevention tips, proper tick removal, and the signs and symptoms of Lyme disease. This curriculum is designed for use in elementary school (grades K and 3), middle school (grade 6), and high school (grade 9). For purchase.

For New Jersey Educators: State Department of Education adopted curriculum already available

LDA (when it was LDANJ) helped to develop and pass the law which developed a state adopted curriculum for use in NJ schools and requires NJ school districts to annually in-service any staff member who has a student with Lyme disease. P.L. 18A 35-5.1-5.3 (1992)

ABC’s Of Lyme Disease LDA pamphlet written for parents and educators

Current research indicates that the Lyme disease bacteria can be transmitted within hours after an infected tick attachment. Failure of parents and teachers to recognize Lyme disease early in its course can result in a child developing a chronic difficult to treat infection in the brain, eyes, joints, heart and elsewhere in the body. Free (shipping costs for large quantities)

New Book for kids with Lyme Disease – BUY BOOK ONLINE

Lyme Disease Is No Fun: Let’s Get Well! written by Mary Wall MS Ed, CCLS, a Columbia graduate student, edited by Colleen M. Smith, a peer-review medical journal production editor and Johns Hopkins grad?each has battled Lyme disease as a child. Author Amy Tan has written the back cover note. Published by Lyme Disease Association, Inc.

The Effects of Lyme Disease on Students, Schools and School Policy

by Patricia V. Smith, President, Lyme Disease Association was
published in School Leader, official publication of the New Jersey School Boards Association, Sept/Oct 2004 issue. LDA has permission to post and reprint the article. Free access

**New! Excerpts from Best Practices in School Health manual, the section on Lyme disease, module 4.**
The excerpted pieces are from interviews with Lyme Disease Association President Pat Smith. “Reprinted with permission from Best Practices in School Health, a publication of Federal News Services, Inc. For more info, please visit [www.fednewsonline.com](http://www.fednewsonline.com)”

**Make Time to Look at Lyme** and **In-service Ideas for Lyme Disease**

**Lyme Times**
The Lyme Disease Association has permission from The Journal of Neuropsychiatry and Clinical Neurosciences to post the following article in its entirety. Free access

**Lyme in the Schools**
Lyme Disease Association website section devoted to Lyme in the schools.

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**LDA Intro – Lyme in the Schools**

The Lyme Disease Association has been providing informational programs for schools since the early 90s, including a 1995 comprehensive (NJ) state wide program for school personnel. LDA has inserviced educators in districts in a number of states and has educated school nurses and special education staff at the local, county and state levels.

LDA has also provided school programs for students, developed an [online prevention powerpoint](#) (40 minutes) which can be used directly from the LDA website in the
classroom for free. It includes 4 modules (10 minutes each), a pre and post test and a pronunciation guide. It is suitable for schools, scouts, camps, and anyone who needs a short course in prevention on Lyme, and it includes easy identification photos of ticks.

The LDA has published a special book for students who have chronic Lyme, “Lyme Disease Is No Fun: Let’s Get Well!, written and edited by young women who both had Lyme as children and with a book cover note from internationally acclaimed author Amy Tan, who is also a Lyme patient. Additionally, LDA provides the ABC’s of Lyme Disease pamphlet written specifically for parents and educators on the problems associated with children. Several doctors and other health care and school specialists have written brief but comprehensive pieces on specific areas of Lyme that affect children.

LDA also lists papers written on Lyme and kids and the schools which can help guide parents through the difficult times of dealing with Lyme disease in their children and having them properly educated in the schools.

Buy Now