President's Blog

LDA LymeLiteracy

Pat Smith, President, Lyme Disease Association, Inc.

LDA President's Blog – CDC Doctor Webinar: Help or Hindrance for Patients?

BACKGROUND During May Lyme Disease Awareness Month, many Lyme groups across the country promote awareness with different projects, programs, and activities to focus on Lyme disease when the *Ixodes scapularis* poppy seed sized nymph ticks begin feeding in earnest.

When the CDC announced a webinar offering continuing education for health care providers for Lyme Awareness Month, some thought it would provide much needed education for doctors about the reality of Lyme disease for patients and what CDC could do to actually help. This assumption was a valid one. The 2nd HHS Tick-Borne Disease Working Group (WG) in its *2020 Report to Congress* had a recommendation that CDC should develop such a curriculum with patient involvement. Federal agency arguments at the WG table said patients could not really be present in the development of such programs– too difficult to get patients incorporated into that aspect. But certainly, as the unanimously adopted recommendation reflected, "the final curriculum shall incorporate feedback from patients, clinicians, and research scientists with expertise/experience that represents diverse scientific and clinical experiences on the full spectrum of Lyme disease and other tick-borne diseases/conditions." So did CDC solicit patient input for this online webinar? By its own admission when asked whether there was patient input at any level of

this webinar, the answer was no, because it was a clinical educational tool.

MY ASSESSMENT After watching this webinar, *Lyme Disease Update and New Educational Tools*, several times, I can honestly say any small benefit this conceivably could have had is clearly wiped out by the continued refusal of government to present the reality of Lyme disease. I saw no meaningful help for physicians nor for patients for their illness, and no information or new tools, only old, repackaged dogma. Read below for details.

CDC WEBINAR PRESENTER The webinar itself was presented by Grace Marx, MD, MPH, credentialed as a medical epidemiologist from Bacterial Branch, Division of Vector-Borne Diseases, CDC. No reflection on her personally, but further research online indicated she is board certified in internal medicine and infectious disease, and a member of the epidemiology intelligence service, credentials CDC did not seem inclined to mention in the webinar—despite bias in the latter two areas during the "Lyme Wars."

TRANSMISSION TIME Following CDC's standard rhetoric, the webinar opening discusses that disease transmission occurs after an infected tick has been attached for at least 24 hours and most transmission occurs after 36 hours. Instead of providing solid information that the longer a tick is attached, the greater the risk of infection, qualifiers were attached– often precluding doctors from making a timely Lyme diagnose and treatment. These qualifiers are not supported by all peer review, especially studies that indicate Lyme bacteria are sometimes found in tick salivary glands at time of attachment. So the time necessary to move from the midgut to those glands (which provides the basis for the 36 hr. estimate) is not a factor. No comment was made on attachment time for other tick-borne diseases—we know, however, there is no safe attachment time for a tick.

DENYING LYME THROUGH GEOGRAPHY Stating that ~500,000 people annually are diagnosed and treated for Lyme, Dr. Marx then showed the map of Lyme's geographic distribution, which only singles out 15 states in yellow – 95% of cases. The old adage, a picture is worth 1,000 words is often used in advertising to communicate ideas that in seconds convey the advertisers message which is, buy what I am selling, no time for the facts. Looking at this map quickly, a harried health care provider or anyone for that matter, can readily conclude Lyme is not a problem in other states. Tens of thousands of Lyme patients have been victims of that erroneous message and continue to be denied or have delayed diagnosis and treatment because of the false assumption that Lyme "doesn't exist" in their state. As pointed out by *MyLymeData Patient Registry,* 72% of patients see four or more physicians before diagnosis and 35% see more than 10. Much of that undoubtedly relates to diagnosis by geography, since patients in low incidence states are often forced to search everywhere in-state to find a doctor not afraid and willing to diagnose and treat Lyme but often end up traveling cross country to get help for their disease.

The WG *Access to Care* 2020 Subcommittee, which I co-chaired, reported to the HHS WG that some of the states believed by CDC to be low incidence for Lyme have some of the highest numbers of insurance claims for Lyme. Citing a Wall Street Journal article featuring a Fair Health study which used a data base of 150 million privately insured individuals, the report indicated in 2016, North Carolina reported 32 Lyme cases to the CDC but made 88,539 health-care claims for a Lyme diagnosis. Also in the report, "…in California in 2016, there were only 90 CDC surveillance cases, while Quest Diagnostics (which is just one of the seven most-used Lyme disease testing labs) reported 483 positive tests, and FAIR Health Data showed insurance claims in the state at close to 47,000, making California one of the top five highest states for Lyme disease insurance claims in the U.S."

Dr. Marx pointed out there are case reports in other states but most are travel related. Several years ago I provided CDC with their own reported case numbers over time from the "other than 15 states." I asked CDC to provide me with data they had proving that most of these cases were travel related. The response: they did not have such data. On the 2nd Working Group, I tried to introduce a Recommendation to Congress that CDC go to the Council of State and Territorial Epidemiologists—who allegedly have control over surveillance criteria guidelines—and ask them to examine the validity of the "diagnosis by geography" portion of the Lyme surveillance criteria based on the inability of patients to get diagnosed due to it. CDC and other agencies at the WG table refused to agree to that reasonable request being put into a recommendation. The only conclusion I can come to is, government does not want Lyme disease to be found outside certain boundaries. They will do and have done everything in their power to prevent it from being found outside their proscriptive boundaries—turning their backs on patients who live there.

ONE DOSE OF DOXY SOLUTION Lyme disease prophylaxis was another topic included in the webinar. In order for a doctor to determine if prophylactic treatment should be used for a bite, 5 questions were listed:

1. Where the tick bite occurred, are ticks likely to be infected with *Borrelia burgdorferi*? (Geography)
2. Was tick removal within 72 hours?
3. Was the tick body flat or engorged?
4. Was it an *Ixodes* (blacklegged tick) tick?
5. Is doxy safe for the person?

Regarding the above questions, many people, including some physicians, do not know what a flat vs. engorged tick looks like. I have even heard stories of doctors telling patients you cannot get Lyme disease from a big tick, which at times, turned out to be a partially engorged tick. Many scientists

who work daily with ticks are reluctant to even identify a tick unless they see it physically, not from a picture, and now doctors are asked to identify ticks and determine engorgement. When I pointed out a fully engorged tick hanging from my mom's leg in the hospital years ago, the doctor told me it was a mole. I was certainly surprised to find moles had 8 legs…. As to attachment time, most people remove a tick immediately upon finding it and have no idea how long it has been attached.

The discussion of prophylaxis centered totally on one dose doxy. As I listened to this discussion, I could "see" the treating doctors and advocates cringing as I was at the CDC trying to justify using that protocol. Although they promote that protocol, Dr. Marx indicated CDC does not recommend tick testing for pathogens as a tool—results can lead to decisions about antibiotic treatment without conducive evidence of patient infection. Interesting statement, since arguments could be and have been made that current tests required by CDC don't provide that evidence either. Although there may be some downsides to tick testing, the only tool in CDC's toolbox is the one dose of doxy protocol—based on a single human trial that did not conclude that single dose doxy could prevent Lyme disease only that it prevented an EM rash in a small group of people. Prescribing one dose of doxy may also interfere with any later testing results.

One of the slides contained a link (I accessed after the webinar) entitled *Guidance for Clinicians: Recommendations for Patients after a Tick Bite.* There is a graphic for tick removal then a statement saying "Save the tick for species ID and degree of tick engorgement (important when determining eligibility for Lyme disease prophylaxis)." Under that is "Post- exposure prophylaxis for Lyme disease," the circumstances explaining when a single dose of doxy can lower the risk of Lyme disease— if:

- the bite occurred in a high incidence state [only map

with 15 states highlighted is shown] or in an area where >20% of ticks are infected with Bb—consult your local health department for details
- the tick can be identified based on adult or nymph blacklegged tick
- the estimated attachment time >36 hours based on degree of engorgement
- prophylaxis can be started within 72 hours
- the patient has no contraindication to doxycycline.

Additionally included in the pdf is a ruler, conceivably for the doctor to judge the size of engorged ticks based on feed time. Almost sounded to me like CDC does not really want to promote one dose doxy as prophylaxis.

VACCINES Patients, advocates and doctors have been concerned that vaccine development has been the force behind refusal to develop safe and effective protocols to treat patients. It certainly has influenced Lyme disease testing protocols—almost the same protocols developed at the 1994 Dearborn conference exist today, with Western Blot banding requirements ("CDC bands") for Lyme disease influenced by the then upcoming vaccines, especially LYMErix. Bands never changed even after LYMErix was pulled from the market by its manufacturer, citing poor sales. The CDC webinar described LYMErix vaccine as both safe and effective, stating it was pulled from the market but no mention of why. Dr. Marx indicated up and coming vaccines could be available in the future. No mention was made of the one in current FDA trials having an Osp A base, yet many felt and still feel that an Osp A base contributed to problems of vaccine recipients that led to the manufacturer withdrawing the LYMErix vaccine.

After 46 years of Lyme disease, the CDC and NIH do not yet know how to accurately diagnose Lyme or treat it successfully, especially when it has prolonged symptoms after 2 weeks of doxycycline. Vaccines are certainly important tools when proven to be safe and effective and when they have been

developed by a transparent process not being run by the vested interests themselves. The CDC wants to have those vaccines at all costs—with billions made by manufacturers of new vaccines, even when there are potentially viable treatments in sight for Lyme but not being explored. NIH is no different in that regard.

RASH, TREATMENT, TESTING You can listen to the webinar sections yourself about the EM rash issue, treatment, and testing. Most are too painful for discussion here by me, but I mention two issues. So much emphasis is placed upon the rash in diagnosis, so rashes should have been explained and pictures shown not just with a central clearing (bull's eye), but also without central clearing (not a bull's eye). On one of the testing slides, it said, "should patients be tested for Lyme disease: look at pretest probability." Then, doctors should ask if patients have been in an area where Lyme is common, were likely exposed to ticks, and have symptoms characteristic of Lyme disease. If the answer to any of these questions is no, pretest probability is low, and testing is not advised. If all three answers are yes, moderate to high probability exists, and testing may be helpful depending on disease stage. Based on that scenario, no testing for those in low incidence states for sure.

COINFECTIONS Webinar co-infection advice is to talk to your local health department about them in your area. I personally ask that you please contact CDC if you do contact your health department and let CDC know how that advice works. Since testing of ticks has not been undertaken in many states, and some coinfections are not known or even reportable, this advice can also be a deterrent to patients receiving proper diagnosis and treatment.

NIH STUDIES The CDC cites only NIH studies of long-term antibiotic treatment and their conclusions which do not show benefit but can be harmful. No mention of recent research which indicates otherwise or of rebuttals to those studies. At

the 2nd term HHS WG table, I fought tenaciously but successfully to keep in the *2020 Report to Congress* papers/opinions which contradicted those NIH findings, as NIH and CDC battled to keep them out.

HOW TO CARE FOR THOSE ON NOT RECOMMENDED TREATMENTS The slide 43 minutes in on "How I can care for my patients who are receiving treatments that are not recommended for Lyme disease," will most likely be the last straw for many. Not recommended by whom? Clearly there are published guidelines that meet National Academy of Medicine (formerly IOM) specs that support clinical judgement in treatment of Lyme disease. The first bullet of six is "to listen to the patient's story," the last bullet is to 'evaluate the risk of Lyme disease and consider an alternate diagnosis." This slide is accompanied by Dr. Marx's commentary not on the slide, "the goal is to demonstrate empathy and compassion…." In my 37 years of Lyme advocacy, I haven't seen that happen yet, and treatments are still withheld.

BOTTOM LINE The non-inclusion of patient input into this webinar is probably a good thing after all. No self-respecting patient or advocate would want their names tied to this webinar, especially when they read the slide below—a slap in the face to the hundreds of thousands of patients whose lives have been saved or vastly improved with long term-treatment and to the brave physicians who put their practices on the line to help patients get better.

Post-Treatment Considerations (slide)

- There is no proven treatment for post treatment symptoms:
    - Additional prolonged antibiotics have not been shown to improve long-term outcomes
- Long term antibiotic therapy has the potential to cause serious side effects, including:

- infectious diarrhea
- antibiotic resistance
- line associated infections

More than **two** courses of antibiotics are **NOT** recommended for the treatment of Lyme disease.

RESPONSIBILITY Who's responsible for this decades-long Lyme fiasco? The blame must be laid at the feet of an alliance of public health and some powerful medical "experts," who have allowed cases to go from 9,908 reported in 1992, to an estimated 500,000 cases annually. While actively seeking to build public trust with the LymeX public-private partnership, public health has not even lived up to its commitment to recommendations they supported on the WG, like CDC including patient input into educational programs. Yet they court the public/advocates so there will be funds allocated to government agencies to ostensibly provide help to patients. Then they use our public dollars to deny many patients the ability to get early diagnosis and appropriate treatment. Disingenuous? With so many lives at stake, that word seems too kind.

Click here for CDC slides and for a video of the webinar

Click here for Tick-Borne Disease Working Group 2020 Report to Congress

Click here for Pat Smith's minority response: Effect of Geographic Restrictions on Lyme Diagnosis

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Slam Dunk for WNBA–Slam for Delle Donne & Lyme Patients

In partnership with the Lyme Disease Association, at the 2014 LymeAid 4 Kids night: All-Star and Delaware 87ers goodwill ambassador, Elena Delle Donne

From LDA President Pat Smith's Blog:

What has happened to one of the best Women's National Basketball Association (WNBA) players is no surprise to the Lyme Disease Association or hundreds of thousands of chronic Lyme patients. Elena Delle Donne, of the Mystics, has been denied by the WNBA league's panel of physicians as having a health exemption due to being at high risk for COVID 19, thus

unable to be paid for exemption status if she does not play the upcoming season. She had a letter from her personal physician who confirmed her high risk status as she has suffered from Lyme for many years, and the team doctor deferred to that physician's appraisal.

Apparently, the league's physician panel decision was based on the CDC's *list of people of any age with* ***certain underlying medical conditions*** *are at increased risk for severe illness from COVID-19.* The **CDC medical conditions list** does not include Lyme. The omission is not surprising when you consider that our government has denied treatment to 20%+ of Lyme patients because it does not acknowledge their condition. This position of the government on chronic Lyme has persisted for decades—Lyme disease as we know it has been around 46 years.

Chronic Lyme can lead in many cases to complete debilitation and even death, so why wouldn't the government classify someone with chronic Lyme as high risk? A high risk admission would provide validity to the claims backed by hundreds of peer reviewed articles published on research in credible institutions that indicate chronic, persistent, Lyme ***might be real.***

The recent discovery of "persisters" and biofilms associated with Lyme disease threaten the house of cards built by the deniers. The patients they have denigrated, mocked, and dismissed over decades might really be sick? These chronic patients might actually need more antibiotics than the ~3 weeks now provided under the IDSA guidelines—guidelines clandestinely, or not so, supported by federal health officials? Guidelines that these officials have tried to remove references to on their websites by removing the name and keeping the contents? As the saying goes, "If it looks like a duck, swims like a duck, and quacks like a duck, then it probably is a duck." From what I hear, the Lyme community votes for the duck. The government continues to endorse IDSA guidelines for diagnosis and treatment.

The government will not however, reference the International Lyme & Associated Diseases Society (ILADS) Lyme Treatment Guidelines, those used by Lyme literate physicians, who use clinical judgment to treat longer-term for Lyme disease if they feel it is necessary.

In fact, a recent NIH FOIA came to my attention which documents a discussion in 2008 between a then NIH official and an HHS employee as to possible removal of the ILADS guidelines from the government's then active National Guidelines Clearing House under HHS's Agency for Healthcare Research and Quality (AHRQ).

The chronic Lyme deniers carefully choose their handpicked biased science often published in their own journals and loudly tout the over generalized Lyme treatment trial conclusions—all are sacrosanct. Their message is clear: No more research is necessary, and no one should question that, especially patients, advocates, and Lyme literate physicians.

Meanwhile, patients cannot get a timely diagnosis, an appropriate treatment, and as Delle Donne found out, a high risk designation. All this denial, yet CDC estimates from studies that there are 300,000+ Lyme disease cases annually in the US alone, and government admits some 15-20% continue to have symptoms. But is it Chronic Lyme? NO. Persistent Lyme? NO. What is it then we ask, 46 years later. Listen to the sounds… of silence.

NOTE: Although LDA President Pat Smith is an HHS TBD Working Group Member, this Blog does not express the opinions of HHS or the HHS Tick-Borne Disease Working Group.

For more information:

Deadspin Article: 'She's Being Discriminated Against': League Says Two-Time MVP's Health Issues Not Serious Enough For Opt-Out

LDA Post 2015: Delaware 87ers, LymeAid 4 Kids Partner For Second Season
– Sevens, Delle Donne and University of Delaware College of Health Sciences to host LymeAid 4 Kids night

LDA Post 2014: WNBA Rookie of the Year Partners with LDA's LymeAid 4 Kids: on CBS TV Sports Network

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Dr. Neil Spector, Inspiration Extraordinaire, Passed Away

Neil Spector, MD
2018 Lyme Disease

Association/ Columbia Conference (LDA archives)

From LDA President Pat Smith's Blog:

It is with great sadness that we in the Lyme community say goodbye to someone whose life was dedicated to helping others through his work as an oncologist and a researcher, Dr. Neil Spector.

Dr. Spector devoted his life to saving the lives of others, first through his work on therapies for cancer patients then his subsequent work on Lyme disease, using the knowledge he gained from his cancer work and from his personal experience with Lyme disease.

He suffered for many years from undiagnosed Lyme disease, a diagnosis that was not even considered in the state he was then in, Florida, where Lyme was not on the radar screen, thanks to government control over where Lyme exists in the US. While his search for a diagnosis was ongoing, he went from a marathon runner to someone who could barely walk 20 yards.

When finally diagnosed with Lyme, he was able to receive treatment, but it was too late for his heart. It had been severely damaged. He lived a number of years with 10% heart function. One day, he was told he had 72 hours to live without a transplant. He was able to get one, and that began a new chapter in his life. He now understood that the medical community in the Lyme world failed patients. They did so by adopting a dogmatic approach to Lyme that created an environment where hundreds of thousands of people, if not millions, heard: there is nothing wrong with you. If enough people tell you there is nothing wrong, eventually you say, maybe it is not Lyme disease. That perception was communicated to higher levels of government and funding agencies. Thus, there has been a lack of urgency about Lyme disease. People

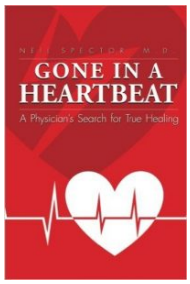
with Lyme are dying all the time and committing suicide. Dr. Spector understood and articulated these observations and truths to all those who would listen and to all those who should listen. (*view his video below for his story & statements*)

I knew him as the man he was, a kind, compassionate, knowledgeable human being, a doctor and researcher who cared for others—not as text book or laboratory specimens—but as real people who were sick and needed medical help, help he provided without the bias and callousness that millions have faced over the past 46 years in the world of Lyme disease.

The biased dogmatic medical science out there cost him and his family dearly. He understood that but took that understanding and turned it into something else, an opportunity to use the humanitarian medical science that he practiced to work on saving countless thousands of lives. He was never too busy to help a patient going through what he went through, sharing his insights on Lyme and heart transplants with patients and their families. He was always ready to share his knowledge with other researchers and physicians, and in 2018, he spoke at the Lyme Disease Association/ Columbia University Lyme conference on ***Applying the Lessons From Cancer Research to the Diagnosis and Treatment of Tick-Borne Diseases.*** He used his own life experiences to positively shape the world around him.

Goodbye Neil, we will miss you and the heartfelt dedication you brought to truly making the world a better place in which to live. We thank your family for sharing you with us and know that your life will continue to inspire others throughout the world.

Watch Dr. Spector in "Lyme & Reason" – Fox 5 News Lyme Special
Renowned Oncologist Neil Spector, MD shares his own personal story of his transition from doctor to patient, and how Lyme disease led to an emergency heart transplant.



Gone in a Heartbeat: A Physician's Search for True Healing by Neil Spector, MD

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Dirty Little Secrets of Lyme Disease

May is Lyme Disease Awareness Month, a time to remind ourselves that Lyme is a disease that has been neglected, minimized, and ridiculed over decades and still continues to be. We all need to redouble our efforts to get an accurate test and to get patients properly treated and treated with dignity. The continued arbitrary ban on ignoring persistent Lyme disease and treating persistent Lyme patients must be

lifted! Here is my take on the secrets of Lyme from 35 years of advocacy.

"Dirty Little Secrets of Lyme Disease"

Where It All Began

Circa 1984 and recently elected to my municipal Board of Education, I found the district in a state of unrest. Students, teachers, others, were developing a heretofore unknown disease. Many in district were hospitalized, rumor had it the disease attacked their brains and they were getting heavy IV antibiotics to try to get them better. I went to the superintendent and said we needed to alert parents, questions were being asked, no one had answers. No one came into the district to talk to us, no government or health officials. The super gave me the go-ahead if I could get info, he would distribute. That search for information began a 36-year chapter of my life that has yet to end.

Pat Smith, President, LDANJ, (Now LDA) 1997, Warren County NJ

I began my journey as a mother with three children, knowing nothing about Lyme disease, and fought a never-ending battle when two of them developed Lyme disease, in a society where mainstream doctors shut the door on Lyme– refused to discuss,

refused to test, refused to treat. Where one of the first questions asked, in front of the child was, so does the child REALLY have Lyme disease or do you just THINK she does; where you had to threaten to get a lawyer when the doctor refused to tell you the results of the Lyme test when it was positive— the office would just keep hanging up. A society where a medical institution with a floor full of children seizing from the disease would take secret videos when the children stopped seizing for periods of time and acted "like normal kids," then those in charge would tell their parents the children were faking. This is what parents told me as they cried, and I held their hands to try and comfort them. Where a supposed famous Lyme expert doctor from the Northeast would tell a 12-year-old child very sick from Lyme disease, see these children (showing the child cancer patients in the hospital), they are really sick, you are not. One mother tracked me down and begged me to help as her daughter cried all the way home and for days afterward and wanted to commit suicide.

What They Did to Our Children

The conduct of those who dealt with our children with Lyme was horrifying. Doctors would tell parents they could not talk about their children's seizures from Lyme disease to anyone, or the children would be put into a psychiatric institution and would not be treated for their Lyme. That was hard for even me to believe early on until I heard of a number of those cases involving both children and adults.

I worked with school districts across the country where children were told they were not sick, they were faking— they just did not want to be in school. Lyme disease was arthritis, it could not affect their brains. Districts tried to prevent long-term sick students from graduating. I went to court to help a couple. In one case, the judge, without prior notice, refused to allow me, a volunteer advocate, to speak on the case, the mother could only pass me notes in court. The

decision was made that the very sick honor student, would not be allowed to graduate/walk in graduation, as she had a few more weeks of work to finish. The judge ruled against her. I could not say anything. It was awful. I told the judge whom I saw afterwards in the hall what I thought of her decision. Looking back, I guess I was lucky I was not charged with something. That student went home, and although direly sick, worked for day and night for many days, finished and graduated with her class with honors and went on to college.

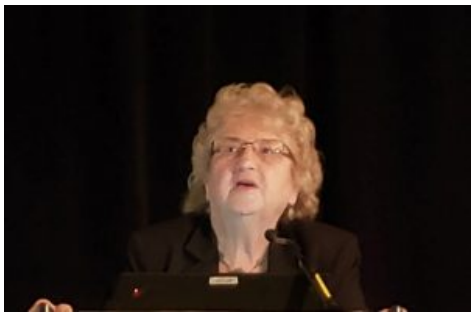
A teacher directly called a child with Lyme who had been out of school for several years and told her she had to be cheating on home instruction, nobody could get that grade and be sick. I will not tell you what I, the mother, said to the school and to her. A child on home instruction was denied entrance into the honor society as she did not (read: could not) participate in any school activities. A district tried to prevent a student whose IQ was off the charts from taking AP courses, one of the many excuses was in their opinion, he was too sick to take AP courses, and then they said they had no teachers certified in AP courses to teach him on home instruction. After I pointed out there was no such certification at that time, he ended up not only taking the courses, but I heard, teaching some of the teachers. Another student was forced to take some of the same exact subjects for 3 years straight, as toward the end of each year he was too sick to attend school the last two months and could not complete the courses. The district did not offer any required accommodations, and he had passed a state-required graduation test. They tried to deny him graduation, but due to their non-compliance with regulations, I was able to not only permit him to graduate but the district paid for his community college. I also heard from doctors, the few who treated then, about child suicides with notes that said no one believes I am sick, my family, my school, even my doctors. (LDA's Lyme: Kid's & Schools Page)

Pat Smith: Voices of Lyme Rally, Westchester 2006

Our Doctors Under Attack

It would take a book and a lawyer or two to talk about what happened to our doctors. We whispered inside doctors' offices about Lyme and its manifestations, after traveling for hours to find someone willing and able to treat, but whose partners would never consider a Lyme diagnosis. Doctors were stripped of licenses, sanctioned, hospital privileges threatened, doctors relocated, and were told they could not diagnose tick-borne diseases unless they were infectious disease physicians or had one consulting—meaning a diagnosis was not going to happen. As an advocate, I spoke to many attorneys to try and keep doctors from being railroaded. Firms would call me in and question me for hours, trying to find ways to help the doctors and also patients who could not get treatment. Doctors would drop out of treating Lyme, some till this day will not touch a Lyme patient, or cannot, due to legal documents. These stories are too legion to repeat. (*Some doctors too afraid to treat…*)

My journey started in NJ but spread all over the US and even to other countries at times. The above are a very few samples of the abuse, neglect, inhumanity and in my opinion, almost criminal behavior surrounding Lyme. (LDA's Controversy Page)



Current Situation

Today, I am a grandmother of four, and I stay in this battle to prevent them and their peers from developing this terrible disease, the politics of which have prevented the science from moving forward. Today, conditions are somewhat better; however, there are still no accurate tests that determine whether someone has Lyme disease, or has active infection. Why? The government has prevented the development/approval of such a test, claiming technology from the 1994 Dearborn meeting is still the best.

Certain portions of the country are still "prevented" from having Lyme disease as the government insists a geographic restriction has to remain in the surveillance definition, a definition that is often used to diagnose, yet the government outright refuses to take any stance to ensure that does not happen. Over the past decades, parents have still been threatened with Munchausen by proxy and children have been taken from their families for being treated by licensed physicians for chronic Lyme disease with long-term antibiotics. Sometimes these cases are a direct result of divorce and custody issues. But it happens, I know, I have had crying mothers on the phone with me.

Doctors continue to be afraid to treat using one of the two Lyme disease guidelines. They continue to be charged. Many in government, mainstream medicine, insurers, and even researchers, who are in positions to stop this abuse, hide behind the "science of Lyme," science which is often long outdated and which has been challenged by new findings from respected scientist and institutions. Yet they refuse to acknowledge this research or refuse to confirm or expand it by approving funding for other studies, which could provide the answers they do not want to acknowledge. Many have positions as peer reviewers and are able to prevent publication of new

findings which would move the field forward. Hand in hand, these entities continue to control the entire picture of Lyme disease from testing to treatment to reimbursement to vaccines, hiding their secrets of Lyme.

What Is The Government Really Doing?

Shockingly, these stories and thousands like them have occurred across the US, and worse, continue to occur. There are some elected officials in Congress and state governments who have bucked the tide and are really helping patients. They are not included here and deserve praise for their efforts by working with the Lyme community to help patients.

But to date, those officials in decision-making public health positions able to "help" Lyme patients have taken actions that are akin to throwing crumbs to those starving for help—placation at its worst. Describing these actions as hypocritical is a gross understatement— the actions, or lack of, exhibit a bias against Lyme patients. It is time that it is recognized for what it is, blatant discrimination against an entire group of Lyme patients with persistent symptoms. More than ever, patients must do everything in their power to influence their legislators to take actions to expose the secrets of Lyme, to stop this discrimination, and to hold these decision-makers accountable. Only then, will there be a test, be effective treatments, and be a cure. Only then, will patient suffering be alleviated.

Bottom Line

Those individuals who suffer with or care for patients with Lyme disease have had to face not only the disease, economic ruin, and family demise, but also ridicule, scorn, and a journey through Hell, never knowing what the next level will be or when their torment will end. It is a journey burned into the soul.

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Polly Murray “First Among Many” Lyme Advocates

Pat Smith, LDA President; Polly Murray; & Corey Lakin, 2nd VP, LDA in 1999 at the first LDA Lyme Conference, Bard College, NY (LDA file photo)

I am sad to hear about the passing of Polly Murray, an artist, and a Mom, who was responsible for realizing something was wrong when she and her family, and many children in her neighborhood, suffered from similar symptoms. Polly’s family and neighbors were either unable to be diagnosed by mainstream medicine or were diagnosed with juvenile rheumatoid arthritis.

She understood that such a disease cluster did not really make sense, and she was even told her own symptoms were psychological. With unflagging courage, she took on the responsibility of alerting public health officials to the issue. This action and her tenacity initiated an official public health investigation that led to identifying a new disease, later called Lyme disease.

I met with Polly several times over the years and found her to be a lovely person who was caring, and unassuming. She took what she did in stride, although her tremendous contribution to science and role in unmasking this “new” disease was not always acknowledged by the experts.

She, above many, deserves the gratitude of everyone: the public, public health, the experts, patients, and especially our children. Her actions alerted this country to a tremendous problem which no one else recognized. Who knows how many more years would have elapsed until Lyme disease was discovered. She saved lives and human suffering.

The Lyme Disease Association mourns her passing and sends condolences to her family who we know must be proud of her sense of responsibility, her courage, and her leadership in the area of Lyme disease, as well as her caring as a Mom. May she rest in peace.

Click here for Polly Murray’s obituary

President's Blog

Shame on the New York Times!

Pat Smith, LDA President

What a tremendous disservice the New York Times has done printing an article in 2019 that carries a message that doctors, supposedly experts in the field, tell parents of children who they diagnose with Lyme " Great news, it's Lyme disease, that's the best thing it could be….It's baloney that you can't cure Lyme disease, it's eminently curable."

Let's cut through the baloney…Lyme disease has been around 44 years in the US that we know about. In 2017, based on CDC's reporting underestimate by a factor of 10, 427,000 cases occurred. Numerous peer-reviewed journal articles cite 15-20% of patients continuing to remain symptomatic or relapsing after treatment with treatment percentage rates of those not diagnosed early believed to be even higher. "Chronic Lyme," which the "experts" call Post-Treatment Lyme Disease Syndrome (PTLDS)– a term that implies no additional treatment should be given–a term couched of course, as a research construct, which any researcher courageous and principled enough to beg the federal government for grant funds to try to get answers for chronic Lyme is probably required to use in his/her studies. Many researchers cannot get a grant if they try to study "chronic Lyme." Word has been whispered through the halls of

DC… *all the research that needs to be done on chronic Lyme has been done*. Now, that is baloney.

A lot of research that has been done on chronic Lyme/PTLDS has been initially or completely funded through non-profits across the country. Those researchers who dare to defy ridicule from some of their "expert" colleagues for dabbling in a "patient invented" condition, have found that there are a number of reasons why Lyme may be chronic, two examples follow. "Persisters," are cells which remain after a course of treatment and are able to survive in a different state in the body, so traditional antibiotic treatments cannot kill them, and they may reemerge under certain conditions to again cause a patient to be symptomatic (K. Lewis, Northeastern; Y. Zhang, Johns Hopkins). Biofilms are aggregates of the bacteria that develop survival mechanisms en masse (E. Sapi, University of New Haven). Some of these same researchers are further examining what other types of antibiotics are able to kill the Lyme bacteria in those states.

Different researchers from various institutions have shown in studies that indeed, the spirochete can be found in animals after antibiotic treatment for Lyme disease, for example, mice, dog and monkey studies (S.Barthold, University of California, Davis; R.K.Straubinger, Cornell; M.Embers, Tulane). Even the NIH did a xenodiagnoses study where clean ticks bit infected individuals who had been treated and yet some picked up the spirochetes that were still in those individuals (A.Marquez,NIH).

I am not a scientist, but respect the science and know that much more needs to be done. I have spent time not whispering conspiratorially in the ears of Congress but educating Congress about the science and the patient problems, so it can make informed decisions about directing more monies and attention to Lyme disease. I am a mother who "vicariously" experienced Lyme disease through two of my children, one who was out of school for 4 full and two partial years, 3 years

with seizures. I am a Lyme and tick-borne disease advocate and have been for ~35 years, since I first encountered Lyme in my school district. I was a board of education member there and dozens of students and staff were sick with a disease which no one talked about, no one provided information about; none from the health department; none from the federal government. I finally went to the military to get information to provide to parents in the district. Fortunately, by the time my kids developed it, I was able to eventually recognize it and get my children diagnosed and treated until they were restored to health to a large degree.

The same Lyme "experts," decided in a testing meeting in 1994 in Dearborn, MI, that only certain Lyme tests would be used, after they carefully stripped away from the tests two highly specific Lyme bacteria proteins that many Lyme patients with late disease responded to, meaning many of the sickest patients no longer met any diagnostic standard. 25 years later, we use this antiquated technology and testing criteria, developed for surveillance, for Lyme disease testing, which picks up ~50% of the cases. To hear the "experts" tell it, if you test positive for Lyme, it's a false positive, and you don't have the disease; if you test negative, you don't have the disease; and if it's equivocal, maybe get retested. Imagine using 25-year old computer technology today! Yet their vested interests and powerful lobbying in the halls of Congress has put the general public at great risk of delayed diagnosis and delayed or inadequate treatment, which can lead to chronic Lyme.

The Times article indicates a month long course of antibiotics is effective regardless of stage. There are two sets of guidelines out there that don't agree on Lyme treatment. The IDSA guidelines, which embodies a few weeks of antibiotics and you are cured, or perhaps you get sent to a psychiatrist or told to go home and live with it. The ILADS guidelines, followed by the community physicians out in the trenches

risking their licenses to treat patients—treatment which allows for clinical judgement. Treating these often difficult cases no one else wants is a thankless job which requires anyone tackling it to climb a steep learning curve with peer education involved. Diagnosis and treatment often requires hours of intensive patient history-taking and record keeping, and follow-ups, 15 minute visits are not an option. These doctors never know when the "experts" who dismiss their own patients with "baloney" will find a way to have medical boards go after them or find some way to tarnish their reputations and prevent them from publishing studies showing the progression of disease. Please do not think all in the medical field have the patients' best interest at heart—not with Lyme disease anyway.

Meanwhile, the epidemic spreads with 50% of the US counties with ticks that transmit Lyme, and that CDC data is already 5+ years old. Not only do deer and small mammals carry those ticks, but also birds, on whose migrating pathways researchers often see the spread of certain ticks and diseases they carry—about ~20 tick-borne diseases and conditions in the US now.

Yes, there are individuals who have been caught early and treated and recovered. Since there is no test for cure that I am aware of, the jury is out on the term "cure" in my opinion. I am happy that the child in the article has recovered.

I am sad, angry and repulsed that the Times would use this type of sensationalism to denigrate those with chronic Lyme and spread a dangerous message that Lyme is not serious and that it being chronic "could be nothing further from the truth." It is that unproven dogma spread by the "experts" that has allowed millions world-wide to become sick and disabled, and some to die an agonizing death. The Times passed up an opportunity to provide a balanced scientific article on the chronic versus non-chronic debate by interviewing some of the researchers cited above for their perspective but chose the

baloney instead.

Click here for NY Times article, *My Son Got Lyme Disease. He's Totally Fine*

Pamela Weintraub is a science journalist and winner of the American Medical Writers Association book award for *Cure Unknown: Inside the Lyme Epidemic*. Psychology and health editor at Aeon and former senior editor of Discover Magazine.

Click here for Weintraub's public response to NY Times article on facebook

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President's Blog

LDA LymeLiteracy

Pat Smith, President, Lyme Disease Association, Inc.

Tick Talk from Washington, DC & the Scoop on Companion Bills

The last year has seen a flurry of activity in Washington. Here's the scoop on the bills, briefings, and bipartisan politics.

2018 HISTORY In the last Congress, May 2018, HR 5900, "National Lyme and Tick-Borne Diseases Control and Accountability Act of 2018'' was introduced into the US House of Representatives by Congressman Christopher H. Smith (R-NJ). Representative Collin Peterson (D-MN) and others cosponsored the bill. The Act will establish the Office of Oversight and Coordination for Tick-Borne Diseases in the Office of the Secretary of Health & Human Services (HHS) to be headed by a director appointed by the Secretary. The bill purposes are to oversee the creation and establishment of an integrated national strategy to overcome Lyme disease and other tick-borne diseases (TBD) and to oversee and coordinate Lyme and TBD programs and activities across agencies and offices of HHS.

The objectives of the Office of Oversight & Coordination for Tick-Borne Diseases include expansion and enhancement of research; expansion and improvement of surveillance and reporting of Lyme and TBD; development of effective diagnostic tests to accurately and timely diagnose, including direct detection tests; development of treatments to cure or improve the lives of those affected with Lyme & TBD/ disorder; design and conduct clinical trials of sufficient size and duration to support clinical recommendations; development of patient registries; documentation of experiences of health care professionals in diagnosing TBD; inclusion of individuals with chronic Lyme disease in clinical, research; coordination with international bodies.

The Lyme Disease Association had significant input into development of the bill, but Congress ended before any action was taken. Lyme & TBD Control & Accountability Act of 2018

2019 EFFORTS Congressman Smith (R-NJ) introduced the identical bill to the above HR-5900 in the new Congress, January 3, 2019. Collin Peterson (D-MN) was onboard as lead co-sponsor of this bipartisan legislation, HR 220. The two Congressmen are co-chairs of the House Lyme Disease Caucus and

have initiated many actions over time to bring help to those afflicted with Lyme and other TBD. In 2017, Mr. Smith's state of NJ ranked 3rd in Lyme disease case numbers (~12% of all Lyme in US) and Mr. Peterson's state of Minnesota ranked 5th (with ~5 ½% of cases). This bill with the same provisos as in the 2018 History above, sits idling in the House Energy & Commerce Committee. Lyme Bill HR 220

In May 2019, the Senate Committee on Aging asked me to provide a phone briefing for them on Lyme and TBD and to provide follow-up material. That Committee is chaired by Senator Susan Collins (R-ME), whose state ranks 8th in case numbers (with 4+% of all Lyme in the US). The Senator's office also held meetings on Lyme with the Midcoast Lyme Disease Support & Education non-profit, an affiliate partner of the Lyme Disease Association, Inc.

On May 23rd, I went to Washington to provide a briefing to a packed room of House staff arranged by Congressman Chris Smith (R-NJ). CDC's Paul Mead, Columbia's Dr. Brian Fallon, Live Lyme Foundation's Olivia & Holiday Goodreau also spoke. Congressman Smith opened with the seriousness of Lyme and TBDs, and his decades of frustration with his work in Congress to get Lyme legislation passed to help patients—legislation similar to other disease legislation he has gotten passed without the strenuous opposition he faced with Lyme. He then spoke about Kris Newby's newly released book, *Bitten*, which credibly documents a biological warfare program in the US which focused on ticks and tick-borne diseases. He announced his efforts to have an investigation to determine what happened, how it happened, and what impact it may have had on the current Lyme and TBD situation. Tornado warning sirens ended the briefing after two hours, a long time in DC. Congressman Chris Smith Guest Blog

Simultaneous to the House briefing, Senator Susan Collins (R-

ME), along with Tina Smith (D-MN), a member of the Senate Health Committee, and Senator Angus King (I-ME) an original cosponsor, introduced a bipartisan effort to improve research, prevention, diagnostics, and treatment for tick-borne diseases. The Tick Act, *Ticks: Identify, Control, and Knockout (TICK) Act*, S1567, is an effort to effort to improve research, prevention, diagnostics, and treatment. The Tick Act incorporates significant language from the HR 220 Smith bill above to establish an office for tick-borne diseases but broadens the scope to vector-borne diseases, which include tick-borne diseases but also mosquito and other insect-borne diseases. The bill also reauthorizes Regional Centers for Excellence in vector-borne diseases for FY2021-2026, $10M per fiscal year, as their current funding runs out in 2021. Additionally, the bill authorizes CDC grants of $20M per year to state health departments to improve collection of data, improve early diagnosis, improve treatment, and raise awareness.

On May 29, Congressman Smith hosted a Congressional Town Meeting on Lyme & TBD in Wall, NJ. Dr. Ben Beard, CDC, Dr. Richard Horowitz, and I spoke for over 3 hours to a packed room despite flash flood and tornado warnings, DC déjà vu. Press coverage of the event was great. Some individuals in positions to help are beginning to take Lyme seriously. Read More

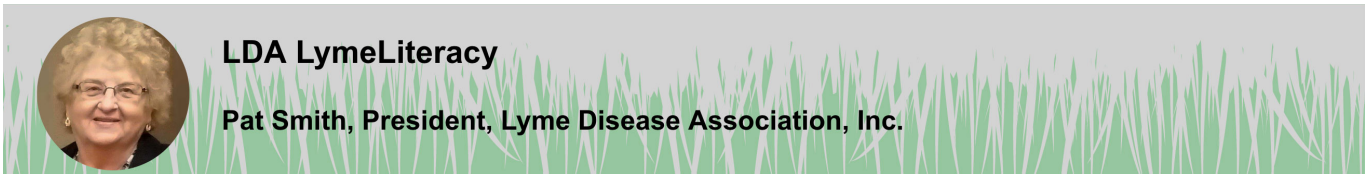
As I traveled to DC to be sworn in for a second term as a public member representing patients on the Health & Human Services Tick-Borne Disease Working Group on June 3, 4, Representative Christopher Smith (R-NJ), with lead co-sponsor Representative Collin Peterson (D-MN) was introducing a companion bill, the identical House version of the Tick Act, HR3073, into the House of Representatives. It was referred to the House Energy & Commerce Committee. APP: ‘Tick Act’ expected to aid fight against Lyme disease

Pat Smith Appointed to New Panel of TBDWG

LDA POSITION The Lyme Disease Association supports all of these bills. With the companion bills, we have to ensure whenever we can both during the process of passage and after passage that the monies will be distributed according to disease burden in the US, a proviso that LDA successfully strove to get included in the legislation. CDC says tick-borne diseases made up 77% of vector-borne diseases from 2004-2016. That is why we need the lion's share of funding to go to tick-borne diseases, especially Lyme disease, with its 427,000 cases in 2017.

No tornadoes occurred during my last Working Group trip to DC; however, I picked up an unwelcome hitchhiker that "latched" on to me in DC, a tick that either decided NJ was a great place to vacation or heard that I was a danger to her kind. My 35 years working to help patients with tick-borne diseases has confirmed that we have to simultaneously deal with diagnosing and treating patients with tick-borne diseases while dealing with the perpetrators of the epidemic– to quote New York Lyme advocate Jill Auerbach, "well, it's the ticks of course!" Let's help these legislators provide government with the tools necessary to make our patients well, to stop ticks, and reclaim our outdoors.

President's Blog

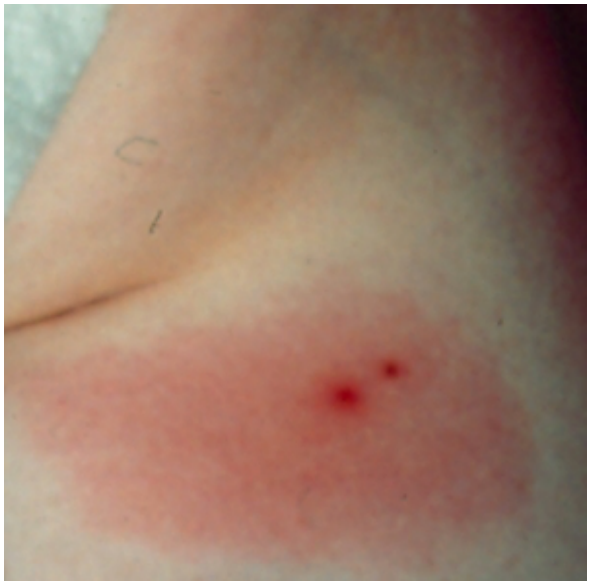
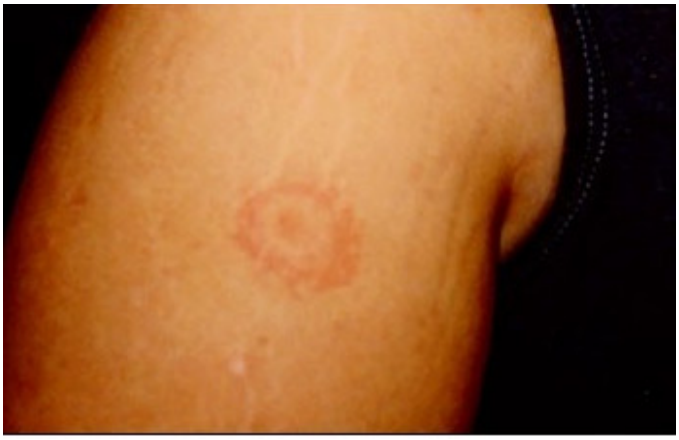


What are Lyme Disease Symptoms & Signs?

Lyme disease symptoms and signs can vary depending on what stage of Lyme disease the patient has. Lyme disease is an infection caused by either *Borrelia burgdorferi* or *Borrelia mayonii* [1] bacteria, the latter recently discovered in the Midwest to cause Lyme disease. Both bacteria are transmitted by the *Ixodes scapularis* tick (deer tick).

What do deer ticks look like?

After a bite from an infected tick, acute or early Lyme disease, the infection is limited to the skin, and symptoms generally develop within a few days to a month. Early signs and symptoms may include a rash, a flu like illness with muscle aches and pains, a fever, malaise and fatigue.

Pic 1: Rash with no central clearing	Pic 2: Bull’s eye rash
	

According to CDC, a rash does not occur in about 30% of cases,[2] but an EM (erythema migrans), an expanding rash with or without a central clearing, often develops at the bite site. Sometimes, the classic bull’s eye rash– a subset of the EM rash–occurs, but only in about 9% of cases[3].

Lyme disease pictures rash.

After Lyme disseminates, which can occur shortly after the bite, a patient may develop late Lyme disease, which can manifest in every system in the body. At this time, a patient may have multiple rashes, and some develop weakness of the facial muscles that looks like Bell's palsy, other peripheral neuropathies and cardiac[4] problems. Choice of Lyme disease treatment with antibiotics depends on length & severity of illness & potential for co-infections.

Late Lyme disease symptoms may be present when a patient is diagnosed, since the patient may have had Lyme symptoms which were not previously recognized or were not attributed to Lyme.[2] Below is a list of possible Lyme disease symptoms & signs.[5] (Printable PDF)

Musculoskeletal: joint pain or swelling or stiffness, muscle pain, shin splints, neck or back stiffness, migrating muscle pain or cramps, TMJ, neck creaks & cracks, tender soles.

Reproductive: testicular pain/pelvic pain, menstrual irregularity, unexplained milk production (lactation), sexual dysfunction or loss of libido.

Cardiac/Pulmonary: chest pain or rib soreness, shortness of breath, heart palpitations, pulse skips, slow pulse, heart block, heart murmur, valve prolapse.

Neurological: muscle twitching, headache, tingling, numbness, burning or stabbing sensations, facial paralysis (that looks like Bell's palsy), dizziness, poor balance, increased motion sickness, light-headedness, wooziness, difficulty walking, tremor, confusion, difficulty thinking/concentrating/ reading, forgetfulness, poor short term memory, disorientation (getting lost, going to wrong place), difficulty with speech, double or blurry vision, eye pain, blindness, increased floaters, increased sensitivity to light or sound or smell, buzzing or

ringing in ears, ear pain, decreased hearing or deafness, difficulty swallowing, seizure activity, white matter lesions, low blood pressure.

Neuropsychiatric: mood swings, irritability, depression, disturbed sleep (too much, too little, early awakening), personality changes, obsessive – compulsive disorder (OCD), violent outbursts, paranoia, panic/anxiety attacks, hallucinations.

Gastrointestinal: nausea or vomiting, loss of appetite, GERD, change in bowel function (constipation, diarrhea), gastritis, abdominal cramping, cystitis, irritable bladder or bladder dysfunction, newly diagnosed irritable bowel syndrome (IBS).

Other: fever, sweats, or chills, weight change (loss or gain), fatigue, tiredness, hair loss, swollen glands, sore throat, difficulty swallowing, swelling around the eyes, & swelling in feet.

[1] Pritt BS, Respicio-Kingry2 LB, Sloan LM, et al. *Borrelia mayonii* sp. nov., a member of the *Borrelia burgdorferi sensu lato* complex, detected in patients and ticks in the upper midwestern United States. 01 November 2016, *International Journal of Systematic and Evolutionary Microbiology* 66: 4878-4880, doi: 10.1099/ijsem.0.001445

[2]Bacon RM. Kugeler K, Mead PS. MMWR 2008 57(SS10); 1-9

[3] Stonehouse A1, Studdiford JS, Henry CA. An update on the diagnosis and treatment of early Lyme disease: “focusing on the bull’s eye, you may miss the mark”. *J Emerg Med.* 2010 Nov;39(5):e147-51. Epub 2007 Oct 18.

[4] Maloney E. What every primary care clinician should know about the diagnosis of Lyme disease. 2017. https://www.lymediseaseassociation.org/about-lyme/medical-lyme/treatment-guidelines

[5] LymeR Primer. https://www.lymediseaseassociation.org/images/NewDirectory/Resources/LDA_Brochures/LymeRPrimer-2013.pdf

LDA LymeLiteracy

News about Lyme & TBD education, prevention, research & government actions

Patricia Smith (Pat)

President of the Lyme Disease Association, Inc. graduated from Monmouth University. She has been involved with Lyme disease issues for 35 + years and is a Member of the HHS Lyme & Tick-Borne Disease Working Group, Member of the Columbia Lyme & Tick-Borne Diseases Research Center Advisory Committee, the Congressionally Directed Medical Research Programmatic Panel on Tick-Borne Diseases, and the Environmental Protection Agency Pesticide Environmental Stewardship Program. She has twice testified before US House Subcommittees on Lyme and is former Chair of the NJ Governor’s Lyme Disease Advisory Council. She has published on and been interviewed for broadcast, electronic and print media on Lyme and tick-borne diseases. (full bio)

President's Blog

2016 Final Lyme Case Numbers: Wondering If Surveillance Can Get More Confusing?

The Lyme Disease Association (LDA) reports that the total number of CDC reported 2016 Lyme cases are now available. Never saw them? Not surprising. In the past, the CDC consistently reported Lyme numbers on a **weekly** basis, as they do with the other reportable diseases in its *MMWR* Report, which is published weekly. The last weekly case numbers reported, however, were reported one year ago for 2016.

The CDC **annual** year end summary of reported Lyme case numbers in *MMWR*– confirmed, probable, and total–were consistently reported in the past about each 3rd week of August for the preceding calendar year. The past two years, that system has changed. In fact, the 2016 numbers came out in November 2017, and they are now very difficult to locate. Thinking I had missed them, LDA wrote and asked CDC at the end of October when/where they were to be published, as the CDC website message about new reporting was unclear about that issue. CDC sent LDA two links when they came out in November.

In the summer, the LDA had asked CDC informally in a phone call why the weekly numbers were missing. CDC indicated it no longer publishes the weekly numbers due to states saying it

was too confusing, and they did not want them published, and The Council of State & Territorial Epidemiologists (CSTE) really had control over what is published in *MMWR*. None of that made sense to me at the time, and it still does not make sense, and no other diseases were affected by this change in practice.

Some questions about the new reported Lyme data include why is the state of Hawaii no longer listed as **N, not reportable**, as it has been in the past, but only as 0 cases? Big difference between the state not reporting a disease and the CDC indicating there were 0 cases, although there could be 0 cases. Why are New York City numbers broken out from New York State numbers in one area and combined in another? Why has the State of New York never had a note on the CDC report indicating that a huge % of its counties are not even included in CDC reported numbers, a question I have posed to CDC in the past. The LDA on its NY case map indicates *"In 2015, 25 NY Counties used a sampling method to determine Lyme disease case numbers. The Council of State & Territorial Epidemiologists (CSTE), charged with surveillance, does not allow CDC to include those estimated numbers to be reported by CDC in the national counts. Thus, NY State had 8,272 Lyme cases including those 25 county numbers by State count, but CDC was only able to report nationally 4,314 Lyme cases for the State of New York."* CDC could use a short note to indicate that only xx counties are represented in its reported case numbers for New York. This omission of reporting at least 25 NY counties in a high incidence state affects the entire total case numbers for the US, plus it can influence policy in New York if those policy makers do not understand the system.

The CDC has a totally new system (new *MMWR* mechanism) in place for the final numbers, called CDC Wonder. That name seems appropriate as this whole issue leaves me wondering why we even have a Lyme surveillance system that is highly inaccurate, beginning with the surveillance criteria, which

CDC disclaims responsibility for—CSTE is responsible. The CDC Lyme surveillance system has already had a huge impact on patients' access to care, another issue for another discussion. Why did CDC change the reporting system to one that is user unfriendly, did not fix some of the issues the old one had which carried over, and perhaps created some new ones.

2016 Final CDC Numbers The 3 states with the highest Lyme case numbers are the same as in 2015, from the Mid-Atlantic region: Pennsylvania, New Jersey and New York, the latter clinging to 3rd place despite at least 25 of its counties not included in the reporting. Also note, Massachusetts, often in the top 5 states in the US in Lyme cases, is not in the top 15. The CDC told the LDA that MA has taken a new approach to surveillance and we would need to talk to MA for details.

The LDA has ranked the top 15 states based on the 2016 CDC Lyme case number summary. The chart below has the top 15 states ranked in order of highest to lowest case numbers, followed by the CDC reported Lyme case number, and then the number adjusted x10 for underreporting.

Links CDC gave to LDA: https://www.cdc.gov/lyme/stats/index.html or you can access them through the new *MMWR* mechanism (go to the to table 2i at the following link) https://wonder.cdc.gov/nndss/nndss_annual_tables_menu.asp

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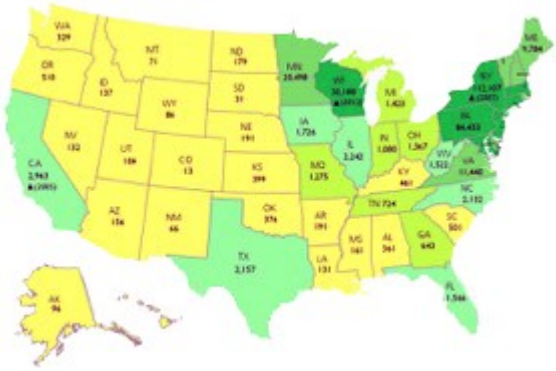
Lyme Total Cases 2016 US 36,429——————————364,290



RANK/ STATE/ CDC REPORTED # ADJUSTED FOR UNDERREPORTING

1. Pennsylvania 11,443——————————114,430

2. New Jersey 4,350——————————- 43,500

3. New York 3,882 *—————————— 38,820

4. Wisconsin 2,295 ——————————-22,950

5. Minnesota 2,126——————————21,260

6. Maryland 1,866—————————— 18,660

7. Connecticut 1,748——————————-17,480

8. Maine 1,487—————————— 14,870

9. Virginia 1,350——————————-13,500

10. Rhode Island 903——————————- 9,030

11. New Hampshire 891————————————- 8,910

12. Vermont 761————————————— 7,610

13. Delaware 506————————————- 5,060

14. West Virginia 368————————————3,680

15. N. Carolina 272————————————2,720

LDA NOTE *“In 2015, 25 NY Counties used a sampling method to determine Lyme disease case numbers. The Council of State & Territorial Epidemiologists (CSTE), charged with surveillance, does not allow CDC to include those estimated numbers to be reported by CDC in the national counts. Thus, NY State had 8,272 Lyme cases including those 25 county numbers by State count, but CDC was only able to report nationally 4,314 Lyme cases for the State of New York.”*

In 2016, NYS reported a total of 7,543 cases, of which CDC was able to report 3,882. Twenty-seven (27) counties were unreported due to the sampling method being used.

LDA Chart of all states in alphabetical order for 2016 final reported case numbers

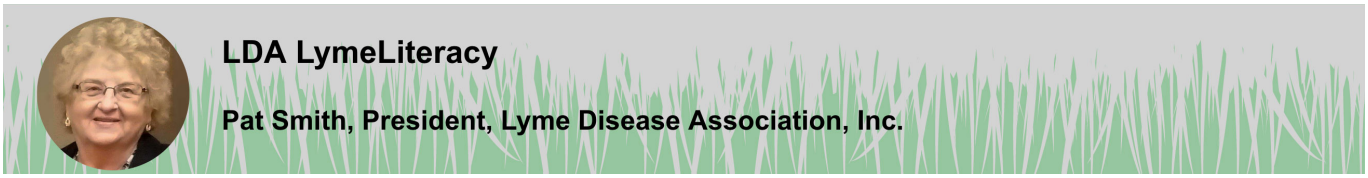
[redacted]

[illegible]

Patricia Smith (Pat)

President of the Lyme Disease Association, Inc. graduated from Monmouth University. She has been involved with Lyme disease issues for 33 years and is a Member of the Columbia Lyme & Tick-Borne Diseases Research Center Advisory Committee, the Congressionally Directed Medical Research Programmatic Panel on Tick-Borne Diseases, and the Environmental Protection Agency Pesticide Environmental Stewardship Program. She has twice testified before US House Subcommittees on Lyme and is former Chair of the NJ Governor’s Lyme Disease Advisory Council. She has published on and been interviewed for broadcast, electronic and print media on Lyme and tick-borne diseases. (full bio)

President's Blog



Saluting Jean F. Galbreath & Harford Cty. Lyme Disease Support Group, Inc.

*r the rights of children to be treated***LDALyme Literacy**: *From the Desk of the LDA President*

The Lyme Disease Association, Inc. (LDA) would like to thank Mrs. Jean F. Galbreath, President of the all-volunteer Harford County Lyme Disease Support Group, Inc., for her dedication and hard work over the past two decades. The HCLDSG was organized by Jean in 1995 and incorporated in 1997. Over time the group has filled a void in education in the area of Harford County, Maryland, a state which ranks 8th in case numbers in the last official CDC reported numbers from 2015.

The Group hosted many activities over the 22 years to raise awareness and even funds for the Lyme Disease Association's Lyme Aid 4 Kids fund for families who are financially unable to have their child diagnosed or begin treatment for Lyme disease. They set up tables with education materials and sold mums and homemade baked goods at local events to raise the funds.

I went to Maryland to testify against a dangerous bill for patient and physicians alike in the Maryland Senate in 2008. Jean and the group led the State effort to defeat the bill, which never made it out of the Senate Committee, fortunately for patients. It would have mandated that the Maryland Department of Health disseminate the latest consensus guidelines to physicians in Maryland—undoubtedly, the IDSA treatment Guidelines which do not recommend any long term antibiotic treatment or alternative treatments for Lyme disease. Click here for history of the bill's defeat – scroll to Maryland

Over time, the LDA has supplied the Group with its materials for free, the LymeR Primer, the ABCs of Lyme Disease, and Tick Identification Card, which they then handed out throughout the area at events, teaching people about Lyme disease symptoms and prevention practices. In 2015, the LDA awarded the Harford County group its *Dr. Lis Heininger Memorial Education Grant* to be used to support its educational programs. The grant is in memory of a late advocate and LDA Chapter Chair from Corning New York, Dr. Heininger, who devoted her life to raising Lyme awareness through tremendous physical hardship that plagued her before she succumbed to her illness. LDA awards the grant to those individuals/organizations who strive in extreme circumstances to help others avoid acquiring Lyme disease. Click here for more information about Dr. Heininger and the grant

In the words of Jean upon receipt of the award, "We are excited to expand our advocating and educational role in the

community and throughout Maryland.” Expand they did. An example of that expansion was a Touch A Truck program held in Street, Maryland, which drew over 1,000 people who were offered information on Lyme and tick-borne diseases by the support group members.

Over the years, I was fortunate to have had the opportunity to meet Jean at several Lyme events and her kindness, humanity, humility, and devotion to eradicating Lyme disease were readily apparent. I feel fortunate to know her and to have been inspired by what she has accomplished under difficult circumstances. We will continue cheering for Jean in the near future. Together, we have helped many people learn about this terrible disease and what it can do to bodies and minds. We have made some headway state by state with people like Jean leading the effort and being a beacon for all to see and follow. Thank you, Jean and Harford County Lyme Disease Support Group, Inc. Know that your work has not gone unnoticed and has touched many people’s lives.