

Johns Hopkins' Aucott Makes Case for Chronic Lyme Disease



John Aucott, Director, Johns Hopkins Lyme Disease Research Center and Associate Professor of Medicine, Johns Hopkins University, published a piece in *The Conversation* providing his insight on the highly controversial topic of chronic Lyme disease.

In the article, Aucott outlines the existence of a population of patients – an estimated 10-20% – with persistent, lingering symptoms months to years after treatment. He details some of his experience treating these patients and provides an explanation of the various challenges that impair the diagnostic and treatment process. Aucott states, “My chronic Lyme patients were sicker and had less hope than the AIDS patients I worked with, but the underlying mechanism of illness remained elusive.”

Aucott emphasizes that while the mechanism of chronic Lyme disease remains unknown, and molecular markers are needed to provide further insights, it is “no longer accurate to simply argue that chronic Lyme disease doesn’t exist.”

[Read Aucott’s full article in *The Conversation*.](#)

Visit LDA’s web page with more information about [the chronic Lyme controversy](#).

LDA President Talks Lyme/TBD on PA Radio

The LDA President, Pat Smith, was interviewed about Lyme & other TBD on Pennsylvania's Forever Johnstown Media. The 25-minute interview aired on 103.5 WNTJ-FM/WNTJ-AM (Johnstown, PA) and 104.5 WNTI-FM/990 WNTI-AM (Somerset, PA) at 8:10 AM on May 20, 2020 and will air on the Sunday Magazine. Included were Lyme case numbers, the Lyme controversy, spread, ticks, other tick-borne diseases, and prevention. Click the audio link below to listen.



<https://lymediseaseassociation.org/wp-content/uploads/2020/05/5-20-20-NATIONAL-LYME-AWARENESS-1.mp3>

[Visit the Forever Johnstown Media website.](#)

Study on Deer Tick Questing for a Host



Blacklegged Deer Tick
(*Ixodes scapularis*)

Examining Adult Tick Behavior

Daniel Cameron, MD, reported in his *Lyme Science* blog on a study that uncovers new information about deer tick questing. The study, from the SUNY Broome Community College's Tracy R. Curtis, et al., was published in *Medical and Veterinary Entomology* and looked at how adult blacklegged ticks (*Ixodes scapularis*) move on public trails with "increasing levels of terrain complexity with a potential host nearby."

The study examined the extent to which adult ticks may actively search (vs. sit-and-wait) for a nearby host. The researchers aimed to determine whether or not ticks could locate the position of the host in natural conditions, as well as to better understand the role of terrain complexity on the distance ticks traveled in a brief period of time (30 min).

What did they find?

According to Curtis "Overall, ticks were more often observed moving (72% of observations) than stationary (28% of observations)." This observation, along with other indicative deer tick questing behaviors captured in the study, led the authors to conclude that adult deer ticks will actively search for their next meal, rather than taking a stationary "sit-and-wait" tactic.

Curtis continued, "Although ticks may indeed utilize a sit-and-wait strategy when no host is detected, this study

suggests that adult *I. scapularis* ticks utilize an active-search strategy when a potential host is detected nearby.”

The Importance of Understanding Deer Tick Questing

Dr. Cameron notes that understanding how ticks move is important in developing ways to minimize our risk of tick bites and infection. The researchers caution readers to be particularly wary of adult ticks – since the study showed their ability to actively seek a host – and because they are found to be nearly twice as infected with TBD as nymphal ticks. Adult ticks will be out questing for their next blood meal in spring and fall while nymphal ticks seek a host in summer.

[Read the study abstract on NCBI.](#)

[Visit Dr. Daniel Cameron's website.](#)

For more information on ticks visit [LDA's Tick Vector page](#) for photos and more.

LDA has received permission from Dr. Daniel Cameron to share this blog information on the LDA website.

Lyme Disease Vaccine Collaboration Announced



Press Release Summary

Specialty vaccine company Valneva SE and Pfizer Inc. announced a collaboration to develop VLA15, Valneva's Lyme disease vaccine candidate, which is currently in Phase 2 clinical studies.

According to a Pfizer press release, VLA15 is the only active Lyme disease vaccine program in clinical development today. The program covers six serotypes of Lyme disease that are prevalent in North America and Europe. The vaccine's mechanism targets the outer surface protein A (OspA) of *Borrelia burgdorferi* (*Bb*), the bacteria that causes Lyme disease. OspA is one of the most dominant surface proteins expressed by *Bb* when present in a tick.

Pfizer states that VLA15 has demonstrated strong immunogenicity and safety data in pre-clinical and Phase 1 studies. In July 2017, the program was granted Fast Track designation by the U.S. Food and Drug Administration (FDA). Valneva expects to report on results from the first Phase 2 studies by mid-2020.

"We look forward to working closely with Valneva to continue advancing the VLA15 program and potentially bring a new solution to patients for this significant unmet need," said Nanette Cocero, Global President, Pfizer Vaccines.

Comments From the Lyme Disease Association

The Lyme Disease Association President, Pat Smith, had this to

say about the announcement: “A safe and effective vaccine for Lyme disease has been a goal for many decades. Unfortunately, many stakeholders, especially some vaccine recipients and providers who were then giving the vaccine, felt there were problems associated with the past Lyme vaccine, perhaps connected to its Osp A base. There are still many unanswered questions about what really happened, and like much that happens with Lyme disease, decades later, we still do not have those answers. The prudent thing for the government and/or vaccine developers to have done would have been to hold public meetings regarding a new Lyme vaccine with all interested stakeholders to hear concerns and answer questions about the development of a new Osp A-based vaccine and what research was done to address the previous concerns and any newly arisen concerns.

In general, much research on Lyme disease has still not been done. In fact, ~46 years into Lyme disease, it ranks below leprosy in the number of clinical trials done in infectious diseases (Goswami et al., 2013). Those who have questioned the safety and efficacy and approval process of the past vaccine have been publicly accused of bringing that vaccine down. When the opportunity for dialogue which engages the Lyme community and all stakeholders has not been offered as part of the approval process, it creates an atmosphere of distrust among those whose trust is necessary to accept a new Lyme disease vaccine.”

Links for You

[Read Pfizer's VLA15 press release.](#)

[Read articles on the history of Lyme disease vaccines.](#)

Lyme Awareness/Secrets of Lyme/LDA 30 Yrs/Working Group/Lyme & COVID-19 Study/ILADS Database

President's Blog



LDA LymeLiteracy

Pat Smith, President, Lyme Disease Association, Inc.

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.

LDA Celebrates 30 Years of Service!

Lyme Disease Association, Inc., LDA, is proud to celebrate 30 years of advocacy and volunteerism to improve research, education, and patient support surrounding Lyme and tick-borne disease.



Dr. Nick Harris (2nd from L) and Dr. Terry MacKnight are flanked by LDANJ Officers Pat Smith and Corey Lakin at a Congressional Forum in Pennsylvania where they were about to speak in 1999. Dr. Harris & MacKnight went on to found [ILADS](#), International Lyme & Associated Diseases Society

Early Years

By 1990, the total US reported Lyme disease case numbers were 7,943 cases – NJ was second in the nation for the highest

number at 1,074 cases – and New York was first. ([1990 LDA MAP](#)) At that time, two groups of patients and doctors, in Northern and Central NJ, were already loosely organized and advocating for Lyme patients – the latter group formed the basis for what is now LDA and was formally incorporated as Lyme Disease Association of Central Jersey Inc. As cases grew, the organization became the Lyme Disease Association of New Jersey Inc. and funded some of the first publicly funded Lyme research in the country on Lyme PCR published in peer review, and some of the first Lyme laws in the country were developed here and passed in NJ (View [article on NJ Legislation Affecting Lyme in Schools](#)).

In 1997, Pat Smith, founder & Chair of a NJ grassroots lobbying group and 12-year departing president of her town's Board of Education, was elected President of LDANJ. In 2000, when US reported cases reached 17,730, she led the Board to a broader focus, with a new name, Lyme Disease Association, Inc. (LDA) – registered in states throughout the US – and focused on a national mission.

Programs

Since its inception, LDA has presented 20 fully accredited CME scientific conferences for researchers and health care providers. It continues to fund tick-borne disease research nationally, provide monies for children without insurance coverage for Lyme treatment, provide on-line brochure ordering for postage-only, host a free online doctor referral system and head the umbrella organization, [LDAnet](#) – a group of 40+ associated organizations nationwide that work together on national issues regarding Lyme and other tick-borne diseases.

Research Grants

In its search for a cure for chronic Lyme disease and other tick-borne diseases, the LDA celebrates funding 119 research projects coast-to-coast at various institutions ([GRANTS AWARDED](#)), and in 2007, LDA partnered with then Time for Lyme to open the first endowed research center for Lyme disease and

tick-borne diseases in the US. To date, LDA-funded research has appeared in 53 peer-reviewed journal publications, ([PUBLICATIONS FROM LDA RESEARCH](#)) helping to move the field forward.

Education Grants

The LDA also aides other organizations and institutions in their missions to educate about Lyme and other tick-borne diseases and has awarded 145 education grants for publications, conferences, billboards, and other activities. LDA has also provided 95 conference scholarships to health care providers, medical students, public health officials, and advocates. ([EDUCATIONAL GRANTS](#))

Shaping Public Policy

LDA President, Pat Smith, is a second-term member of the Health and Human Services [\(HHS\) Tick-Borne Disease Working Group](#) (TBDWG) established by Congress in 2016. ([LDA'S TBDWG PAGE](#)) She was instrumental in the creation of the original Lyme legislation and its passage through the US House of Representatives and then its revision as it was placed into the 21st Century Cures Act. LDA led an advocacy effort to get the legislation passed in that Act which created the existent Working Group. She has also testified before 2 of the US House of Representatives Subcommittees on Lyme disease and effects on patients. She has also helped to write and has testified before many state legislatures on Lyme disease legislation. ([TESTIMONY](#))

Fiscal Responsibility

The LDA has always consisted of patients and families of patients, volunteers who run the organization. It has never had employees but has consultants who provide expertise in necessary areas. The LDA averages 97% of its funds going to its programs. As LDA celebrates 30 years, we look for help from across the US to help unlock the secrets of Lyme and other tick-borne diseases.

30 Years of Service in Photos



LDNJ Freehold Raceway (NJ)
Lyme Disease Association of Central New Jersey
Lyme Disease Awareness Day



Pat Smith, President, LDANJ, has introduced Congressman
Chris Andrews (NJ) who co-sponsored with LDANJ the
Lyme Disease Forum for Federal Officials held in NJ in
2019.



Lyme Awareness Press Conference; Pat Smith, LDA, at Podium



Congressman Chris Smith (NJ); Pat Smith (LDA), Brian Dashore & Mother



LDA Celebrates 20 Years of Scientific Conferences



Pat Smith, LDA, and Brian Fallon, MD, MPH, Columbia University



LDA Partner Organizations Throughout the US



Smith, LDA President, Joe Larisa, Chief of Staff to Governor Almond, Lisa Larisa, RI Coalition at the bill signing ceremony in 2002.



Congressman Chris Smith (R, NJ); Pat & Rich Smith, LDA



LDA / Columbia Scientific Conference

**Conference/WG Meeting
Clips/Neuropsychiatric
Lyme/COVID-19/House Lyme
Caucus/Monies for
Researchers/WG Meeting
Summary/Tickmojis**

**President at COVID-19 Event:
Lyme is Serious!**

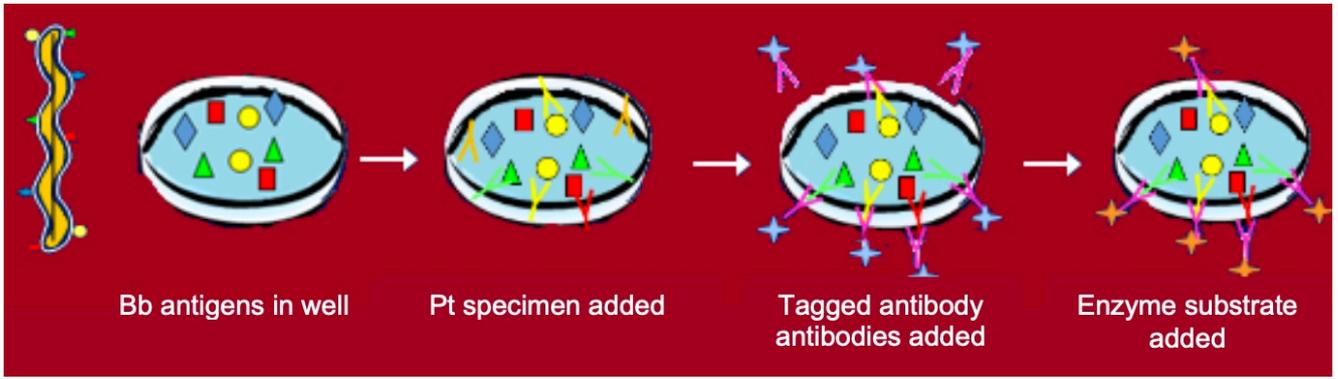
Current Lyme Disease Testing Problems

Elizabeth Maloney, MD, explains current Lyme disease testing issues, including the ELISA and Western Blot, sensitivity and specificity of the testing, and the problems associated with the two-tier testing recommended by the CDC. It begins with the general characteristics of diagnostic testing

The Summary states: "Serologic testing for Lyme is inaccurate. While the inadequate sensitivity of ELISA and Western blot tests is the primary problem, imprecision and the lack of clinical validity contribute to the poor performance of two-tier testing in clinical settings. Although the high specificity of the CDC two-tier strategy works well for epidemiologic purposes, the testing sequence reduces the overall sensitivity, thereby limiting its clinical effectiveness. While positive results on two-tier testing in an untreated patient who has symptoms of Lyme disease would confirm the clinical diagnosis (and it would be a mistake to label such results as "false positives"), negative results do not rule out Lyme disease."

See full article by Elizabeth Maloney, MD here: [Applying Basic Concepts in Laboratory Testing to Serologic Testing for Lyme Disease](#)

See International Lyme & Associated Diseases (ILADS) Controversy & Challenges Page – [Issues with Diagnosis & Diagnostics](#)



ELISA Test: The original whole cell sonicate test