

Congressman Christopher H. Smith Guest Blog

May Awareness LDA Guest Blogger



Congressman Christopher H. Smith (NJ-04), elected in 1980, is currently in his 20th term in the U.S. House of Representatives, serving New Jersey's Fourth Congressional District.

Since the early 1990s, Smith has authored comprehensive amendments and legislation to increase federal funding for Lyme research and enhanced treatment access for Lyme patients. Smith co-founded and currently co-chairs the bipartisan Lyme Disease Caucus, which serves as an incubator for Lyme disease legislation and promotes Lyme disease awareness in the House of Representatives.

Smith's legislation ([H.R. 611](#); [H.R. 2557](#); [H.R. 1179](#); [H.R. 741](#); [H.R. 3427](#)) to create a Tick-Borne Diseases Advisory Committee served as the prototype and was ultimately incorporated as Section 2062 in the **21st Century Cures Act (P.L. 114-255)**. Section 2062 established the first federal

Interagency Lyme and Tick-Borne Disease Working Group dedicated to facilitate research, development, and collaboration on Lyme disease. In November 2018, the Working Group released its first report to Congress, stating: “[i]ncreased Federal funding, prioritization, and leadership are needed to reverse the alarming trends associated with tick-borne diseases.” Smith is already working on legislation to help the federal government pursue this mandate.

A Message from Congressman Chris Smith

Dear Friends:

As the co-chair of the bipartisan House Lyme Disease Caucus, I am deeply grateful and inspired by the Lyme Disease Association, other NGOs, family caregivers, Lyme literate docs, and—above all—the patients who continue to press our government to invest more in research for a cure, the prevention and best treatment options for those with Lyme.

Each day, the Caucus works to advance initiatives to help the overwhelming number of patients currently suffering from Lyme disease; the more than 300,000 Americans who will be diagnosed with Lyme just this year alone; and the hundreds of thousands who are unknowingly suffering from Lyme due to misdiagnosis or lack of clear symptoms.

The most prevalent vector-borne disease in the U.S. today, Lyme can lead to disseminated infection and can affect every system in the body, including the central nervous system. Later symptoms of Lyme include neurological problems such as facial paralysis, memory loss and heart symptoms such as heart block and inflammation of the heart muscle. Lyme has been reported in every state in the U.S. My state of New Jersey has a particularly high incidence of Lyme, yet, unfortunately incidences of Lyme are rapidly increasing across the nation.

We have made some important strides combatting Lyme disease in Congress—funding research through the Department of Defense and the Centers for Disease Control and Prevention. But Lyme is now an epidemic and much more must be done to help those exposed to and suffering from Lyme.

The federal Tick-Borne Disease Working Group—created by provisions I wrote and helped secure in the *21st Century Cures Act (P.L. 114-255)*—released its inaugural report to Congress late last year. The federal Working Group admitted that “increased Federal funding, prioritization, and leadership are needed to reverse the alarming trends associated with tick-borne diseases.” They added: “Federal funding for tick-borne diseases is less per new surveillance case than that of other diseases.”

We need greater funding and resources to address the many remaining roadblocks to proper Lyme disease diagnosis and treatment. As the author of new legislation, H.R. 220, the *National Tick-Borne Diseases Control and Accountability Act*, I am working hard to boost scientifically-based answers to provide solutions, and to bring greater federal support to the patients living with this debilitating disease.

I am also looking into highly disturbing claims—shocking—and data revealed in a new book released just last week, *“Bitten: The Secret History of Lyme Disease and Biological Weapons.”* Authored by Kris Newby, a Lyme Disease survivor and producer of the compelling Lyme Disease documentary *“Under our Skin,”* the new book, documents serious allegations about possible complicity by U.S. government officials—as far back as the 1950s and 60s—in the development of Lyme Disease.

I’ve read the book—couldn’t put it down. The persuasive and frightening information detailed in the book requires a serious and comprehensive investigation to get to the truth and determine if there is any legal culpability in the spread of Lyme Disease. I have raised this issue with the President

and Cabinet members of several government agencies, and have, along with Collin Peterson the democrat co-chair of the Caucus—requested an Inspector General investigation through the Departments of Defense, Agriculture and Homeland Security.

We owe it to the overwhelming number of individuals suffering from Lyme Disease to go wherever the facts lead. Transparency is key. We must establish the truth of the origins of Lyme disease and be fully prepared to treat, cure and prevent this insidious disease in the future.

Chris Smith.

Chris Smith is a Republican congressman serving New Jersey's Fourth Congressional District. Smith, who has written more laws than all but one of the current 435 members of Congress, is the cofounding, cochairman of the Lyme Disease Caucus in the House of Representatives and has successfully pushed for increased federal funding of Lyme research.

**CDMRP Highlights Tick-Borne
Disease Research Program**

Awards for 2017

Since 2016, the Congressionally Directed Medical Research Programs (CDMRP) Tick-Borne Disease Research Program (TBDRP) has received a \$5 million Congressional appropriation each year to allocate to awardees focused on Lyme disease research or research on other tick-borne disease (TBDs). Awards address at least one of four TBDRP focus areas which include diagnosis, treatment, prevention, and pathogenesis. The projects awarded are focused on lessening the burden of TBDs, to improve treatment options and diagnostic assays, or to investigate the pathogenic mechanisms of the causative agents of TBDs.

Four awards were given in Fiscal Year 2017, all with a primary focus on Lyme disease. Recipients of the awards were Dr. John Belisle, at Colorado State University; Dr. Troy Bankhead, at Washington State University; Dr. Nicole Baumgarth, at the University of California, Davis; and Dr. Yang Wang, at MassBiologics, University of Massachusetts Medical School.

LDA President, Pat Smith, is on the CDMRP Programmatic Panel.

For a full description of the awards and projects please visit CDMRP articles here:

https://cdmrp.army.mil/tbdrp/research_highlights/19lyme_disease_awareness_highlight

L. Johnson on Meaningful

Patient Representation on the next TBDWG

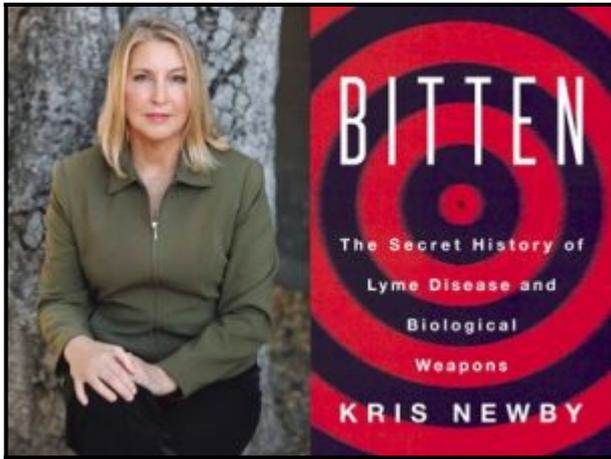


Lorraine Johnson, JD, MBA, Chief Executive Officer of LymeDisease.org delves into the importance of meaningful patient representation on the Federal HHS Tick-Borne Disease Working Group (TBDWG) in her latest blog. This is especially important as we await the announcement of panelists to the new TBDWG charged with the next report to Congress due in 2020. A recent patient survey conducted by lymedisease.org found “To be a meaningful representative, patients chosen for a

panel should: a) have or be a caregiver to a patient with chronic Lyme disease and b) should be an officer or director or someone vetted and approved by a recognized and trusted patient advocacy group (PAG) or someone approved by a PAG.” Read the entire blog by Lorraine Johnson here:

[LYMEPOLICYWONK: Who represents Lyme disease patients? Why it matters.](#)

“Bitten” Book Review



The debate over the prevalence of Lyme disease and whether it exists in a chronic form has raged for decades. Kris Newby's well researched book provides documented evidence that the suspicions of disease sufferers, their advocates, and treating physicians deserve investigation. The properties of the pathogen itself and its ally, the tick, appear to be part of our nation's biowarfare studies.

Swiss American scientist Willy Burgdorfer is acclaimed for identifying the spirochetal bacteria which causes Lyme disease. Indeed, the pathogen bears his name, *Borrelia burgdorferi*. Yet as the author discloses through filmed interviews and archival reviews, there were other aspects to Willy's research. Employed by the US government and headquartered at Rocky Mountain Laboratories, Burgdorfer was enmeshed in biological warfare projects. Ms. Newby discusses his work in Switzerland for the American government which led to the identification of a new strain of *Rickettsia*, a pathogen if crossed with *Borrelia* might well complicate treatment and thus be a candidate for biowarfare. Interviews by Ms. Newby with American researchers on the topic of the *Rickettsia*, dubbed the Swiss agent by Dr. Burgdorfer, did not shed any light on the mystery pathogen whose existence seems to be buried in the past.

Ms. Newby's discovery of tick drops and the experimental release of ticks document ongoing biowarfare research and questions the consequences if studies go awry. The prevalence of new diseases and the expansion of tick territories are examined in the context of now revealed government studies.

Ultimately, whatever mix of causes is responsible for the Lyme and other tick-borne diseases epidemic in the US, the

solutions, as strongly stated by Kris Newby, lie with better science, advanced research and proper funding.

[Click here](#) for YouTube video of Under Our Skin, Director, Andy Abrams and Kris Newby discussing her new book.

[Click here](#) to purchase *Bitten* on amazon.com

[Click here](#) for other purchasing options of *Bitten* on HarperCollins.com

Richard I Horowitz MD, PLLC Guest Blog

May Awareness LDA Guest Blogger



Dr. Richard I. Horowitz, MD, PLLC, is a board-certified internist and medical director of the Hudson Valley Healing Arts Center, where he has treated over 13,000 Lyme and tick-borne disease patients during the past 30 years. He is the author of two best-selling books, *Why Can't I Get Better?* & *How Can I Get Better? An Action Plan for Treating Resistant Lyme and Chronic Disease*. Dr Horowitz was also a member of the HHS Tick-borne Disease Working Group and Co-chair of the "Other Tick-borne Diseases and Co-infections" subcommittee which provided recommendations to Congress to improve the care of those suffering with tick-borne disorders.

Why Patients with Chronic Lyme-MSIDS Should Have Hope



I just got back from the inaugural conference of ISEAI (International Society For Environmental Illness) at the CIVANA spa in Carefree, Arizona. I was surrounded by group of approximately 300 integrative health care providers from across the US who all met in the desert with one primary focus. These doctors all wanted to know how to treat their sickest and most resistant patients with chronic Lyme symptoms who were also being adversely affected by environmental illness. People were showing up in their practice with Lyme and co-infections like Babesia and Bartonella, as well as testing positive for environmental toxins including mold, heavy metals, pesticides and persistent organic pollutants. These infections and toxins were making their patients extremely ill. They oftentimes complained of chronic fatigue, insomnia, migratory muscle, joint and nerve pain, along with neuropsychiatric symptoms and cognitive difficulties. To make matters worse, the inflammatory response driven by the infections and toxins was oftentimes complicated by poor detoxification pathways, gastrointestinal dysfunction (leaky gut, food allergies, imbalances in the microbiome), autoimmune manifestations, hormonal and mitochondrial dysfunction, mast cell activation, as well as POTS/dysautonomia and PTSD. This picture of patients with complicated illness is unfortunately becoming the norm, not the exception.

Health statistics have shown that half of American adults suffer from one chronic disease, and one third of all

childhood diseases have now been linked to environmental exposures (i.e., ADD, Autism Spectrum disorder, cancer). Lyme is spreading in epidemic proportions across the US. That's the bad news. The good news? There are answers. Let me share a few of them to give you hope.

I went to the ISEAI conference to discuss my two recent published papers for the treatment of chronic Lyme disease/PTLDS. The first was: Precision Medicine: retrospective chart review and data analysis of 200 patients on dapsone combination therapy for chronic Lyme disease/post-treatment Lyme disease syndrome: part 1 (Horowitz, R., Freeman P. International Journal of General Medicine 2019:12 101–119) as well as part 2 of our paper titled: Precision Medicine: The Role of the MSIDS Model in Defining, Diagnosing, and Treating Chronic Lyme Disease/Post Treatment Lyme Disease Syndrome and Other Chronic Illness. (Horowitz, R.I.; Freeman, P.R., Healthcare 2018, 6, 129).

These two articles give an overview of how the recent scientific discoveries by Dr Y. Zhang, Dr Eva Sapi and Dr. Kim Lewis can be taken from the laboratory bench and effectively moved into the clinical setting (translational medicine). I devised treatment protocols for the biofilms and stationary borrelia "persister" cells discussed by these researchers based on my prior experience of working with mycobacterium drugs. Fortunately, it worked. And keeps on working for many. Doxycycline, rifampin, dapsone with 3 different biofilm agents (Stevia, Biocidin and oregano oil) has now kept my wife in remission for almost 2 years. She was a classic "MSIDS" gal. She suffered from Lyme, Babesia, Bartonella, Mycoplasma, food allergies, Candida, leaky gut, mast cell activation disorder, POTS, adrenal dysfunction, hypothyroidism, hypoglycemia, metabolic syndrome, sleep apnea, PTSD, heavy metals and mold exposure with mitochondrial dysfunction. Now, after addressing every abnormality on the MSIDS map, and treating her with dapsone combination therapy, she has her life back. There is

hope for the ones we love, and many others in my practice who kept relapsing are also now in remission.

So what are the next steps? Trying novel Bartonella 'persister' regimens (based on Dr Zhang's recent published research) for resistant Bartonella, and new antimalarial regimens for resistant Babesia. I also learned at ISEIA that Annie Hopper's limbic retraining may be the answer for some of my sickest, most sensitive patients with POTS, mold, chemical sensitivity and resistant tick-borne disease. We now have even more tools in our toolbox, and I have even more hope. So should you.

James L. Occi, MA, MS Guest Blog

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James (Jim) L. Occi, MA, MS is a microbiologist who has been involved in searching for new antibiotic entities for almost 30 years. He has done research in big pharma for over 20 years and as a research microbiologist at New Jersey Medical School in the Department of Emerging Pathogens (Newark). Jim has recently joined the New Jersey Department of Health. Jim is pursuing his PhD at Rutgers University wants to be a medical entomologist when he grows up. For his thesis, Jim is studying tick-borne diseases in New Jersey tick populations. He has a BS and MA in Biology from Montclair State University and an MS in Microbiology from Seton Hall University.

“Scientists Predict a Bad Year for Ticks.” Oh Really?

I am often asked: “Is it going to be a bad tick year?” My answer is: “I have no clue”.

And why don't we (tick researchers) have a clue? Multiple reasons. First of all, there are more than one species of tick that commonly bite humans and they all have different habits and lifestyles. Secondly ticks have multiple stages that come out at different times of the year. But the most important reason is that there are very few surveillance programs. How can we predict that any given year is going to have more ticks than another if no one is “counting” ticks???

In other words, we can't predict a “bad year” when we don't

know what we had previous years. The bottom line is that we need a surveillance program for ticks. What is surveillance?

Surveillance is the repeated sampling of a given area over time in a systematic fashion using standardized protocols. But it does not end there. The data needs to be analyzed and disseminated to public health professionals. Then the data must be acted upon. What kind of action? At the very least posting signs reading: "Tick infested area. Use the proper precautions."

Lets look at New Jersey's mosquito control infrastructure as a model. Briefly, biologists monitor mosquito populations two ways: by using various traps that attract adults and looking at bodies of water (small and large) for larval for activity. There is also a system in place where mosquitoes are sent to a central state lab from every county in NJ and tested for the various viruses that mosquitoes can transmit to humans and animals. If adult mosquito populations reach nuisance levels, or if populations of mosquitoes are found infected with certain viruses, a control program is implemented. This has been going on since the early 1900s in New Jersey.

What about a tick surveillance program? First we have to consider the differences between ticks and mosquitoes and how a mosquito finds a host, for example. Basically mosquitoes come to you. With ticks, we enter their turf and when we come in direct contact with them (on a trail for example) they climb onto us. Surveillance is different too. With mosquitoes you set traps and hope the mosquitoes come to the traps. With ticks, the collector has to enter the ticks "zone" if you will and make pretend he or she is a host by using a cloth that is dragged over the vegetation in the hopes that the tick will clamp onto it.

These differences aside, tick surveillance can be done. But it is going to take money, people and training. In the next blog I will outline a few different tick surveillance programs

already in existence.

5th Annual MLDSE Conference was a success!



The 5th Annual Midcoast Lyme Disease Support & Education Conference was another success! The conference was held on Friday, April 26th at the Augusta Civic Center, in Augusta, Maine. Admission was free for the all day event. The positive feedback from all who attended, including community partners and exhibitors, was as Paula Jackson Jones, President of MLDSE reports, “truly overwhelming”.

The conference hosted 16 speakers, all experts in the various fields of Lyme and other Tick-borne Diseases from across the country. Dr. Thomas Moorcroft presented as the Keynote Speaker. Pat Smith, President of the Lyme Disease Association

Inc., presented a national update about how prevalent Lyme and tick-borne disease is becoming. MLDSE is an affiliate member of LDANet, and LDA provided support for the conference through an education grant. Educational conferences provide both medical providers and patients exposure to more education, better diagnostic and treatment options and a clearer understanding of why some patients improve and some do not.

For those who could not make the conference, speaker PowerPoint presentations (only) will be uploaded to the conference website in the next week: conference2019.mldse.org. Mark Your Calendars now for the 6th Annual MLDSE Conference, Sat April 11th, 2020 at the Augusta Civic Center!



Columbia News Features Dr. Fallon & His Lyme Book Wins Award



Brian Fallon, MD – Oct. 27 & 28, 2018, LDA/Columbia Annual Scientific Conference (LDA file photo)

Columbia News, April 30, 2019, by Carla Cantor, “When Lyme Disease Doesn’t Go Away” is an interview with Brian A. Fallon, MD, Director of the Columbia University Lyme & Tick-Borne Diseases Research Center. The article discusses his early career and his work on Lyme beginning in the early 90s and the formation of the Center, a joint effort between then Time for Lyme (now GLA) and the Lyme Disease Association, Inc. and the Columbia Board of Trustees. He discusses persistent Lyme.

His book, [*Conquering Lyme Disease: Science Bridges the Great Divide*](#), with co-author Jennifer Sotsky, is also featured in the article. LDA has just learned from Dr. Fallon that the book has been selected as a “Winner, 2019 Choice Outstanding Academic Title.” *Choice* reviews thousands of books each year using expert unpaid scholars and prepares a list which is used by many academic institutions, large public libraries and others to purchase books for their libraries. *Choice* is published by the Association of College and Research Libraries.

Dr. Fallon is a member of the Lyme Disease Association’s Scientific & Professional Advisory Board.

<https://news.columbia.edu/news/when-lyme-disease-doesnt-go-away>

Lyme Patients File Civil Suit Against Insurers/IDSA/IDSA Panelists: Update!

A revised complaint has been filed for the Torrey et al v. Infectious Diseases Society of America et al lawsuit initiated in 2017. The initial lawsuit was filed on behalf of Lyme disease patients who say they have been denied care which resulted in harm under existing insurance and medical protocols.



Plaintiffs claims include injury by the IDSA, Insurance Defendants, and the IDSA Panelists “because they were forced to pay for their treatments, were forced to pay all expenses associated with treating their Lyme disease, were forced to travel long distances for treatment, were forced to try to find doctors who would treat them, and were unable to work or earn money because of their debilitating illness.” Further, because Plaintiffs “were not timely diagnosed or treated, they now suffer long-term complications and are forced to continue to pay future medical costs for treatment and out-of-pocket expenses to receive this treatment.”

The suit was filed by 24 patients, charging six doctors (IDSA Panelists) and eight insurers with violating the Racketeer Influenced and Corrupt Organizations Act (RICO). The

defendants are the Infectious Diseases Society of America, six physicians who participated in writing the IDSA's Lyme guidelines or assisted with enforcement of the IDSA guidelines, and the insuring companies including: Blue Cross And Blue Shield Association, Anthem, Inc., Blue Cross And Blue Shield Of Texas, Aetna Inc., Cigna Corporation, Kaiser Permanente, Inc., United Healthcare Services, Inc., and United Health Group Incorporated. A judge previously rejected the claim of fraud under RICO in Torrey v. IDSA, but allowed the Plaintiffs (patients) to submit a new version of the suit.

The litigation is proceeding in U.S. District Court in Texarkana, Texas and a trial is currently scheduled for June 24, 2019 before District Judge Robert W. Schroeder III.

To read the Plaintiffs' First Amended Complaint filed March 25, 2019 click [here](#).

Two-Tier Testing for Lyme Disease: How it Evolved



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Internal & Critical Care Medicine, Private Practice, Pawling,

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The Two-tier method of testing is used in the Lyme Disease Surveillance Criteria developed and adopted by the Council of State & Territorial Epidemiologists and used by the Centers for Disease Control and Prevention (CDC). This entails a screening test (e.g., Lyme E.L.I.S.A. – Enzyme Linked Immuno-Sorbent Assay) in which a positive or borderline result is followed by a Western blot for confirmation. This protocol was specifically intended strictly for epidemiologic purposes (e.g. to track numbers of cases in a given geographic region and to track the spread of the disease in to other geographic regions).

This type of schema was originally utilized with quite satisfactory results for the H.I.V./A.I.D.S. epidemic. It worked well because the screening test was some 95% sensitive.

It is widely recognized that the screening test for Lyme disease is at best some 50% sensitive. As a result, persons who may have Lyme disease are often missed since Western blot (which may show important clues or even conclusive evidence of infection) is not done, per CDC advice. As a result, individuals may go months, years, or decades without diagnosis or treatment and may become progressively (and sometimes irreversibly) damaged.

Compounding the situation, many physicians, health plans, vertically integrated health care systems and insurers misuse the Two-tier Testing schema as the sole criterion for a

diagnosis of Lyme disease, despite CDC's 'lip-service' that the diagnosis of Lyme disease is a clinical diagnosis with supportive data from the laboratory.

The Two-tier Testing schema was brought forth as a result of the Second National Conference on Lyme disease testing under the auspices of the Association of State and Territorial Public Health Laboratory Directors (ASPHLD), the state health department, the National Committee for Clinical Laboratory Standards (NCCLS), Council of State & Territorial Epidemiologists (CSTE), CDC, NIH, and FDA in Dearborn, Michigan in 1995. Ostensibly the result of a 'consensus', actually this was forced through against the objections of many of the scientists, physicians and laboratorians who had been convened there. It was made to appear as though it had been a 'consensus' whereas this was not the case (1). No minority report was accepted.

Clinicians often mistakenly believe that a negative screening test for Lyme disease 'rules out' Lyme disease. Due to the mischief that has resulted from this situation, the states of Virginia and Maryland have passed legislation requiring physicians to advise patients, in writing, that a negative screening test does NOT rule out Lyme disease.

Direct detection methods that do not depend on antibody methods have been developed for Lyme disease. One methodology, PCR (polymerase chain reaction), is accepted widely for the diagnosis of virtually all infectious diseases, but inexplicably, its use for the diagnosis of Lyme disease by detecting its DNA, is officially discouraged by CDC for the clinical diagnosis of Lyme disease. This method would allow for early diagnosis before diagnostic antibody levels can be mounted and also for the disease at any stage, including for persons who are seronegative. Although the method is not as sensitive as one would like (due to the low density of the DNA of the Lyme organism in bodily fluids), it remains at present the only well validated method of direct detection that is

readily available to clinicians and could be more widely utilized.

(1)Conflicts of Interest in Lyme Disease: Laboratory Testing, Vaccination, and Treatment Guidelines. Special Report. Lyme Disease Association, Inc. 2001.