SB103- The Patient's Access to Integrative Healthcare Act of 2020

Dear Senator Eckardt, Klausmeier & Committee Members,

Thank you for your continuing efforts to help Maryland residents receive adequate treatment for their various health issues. We especially appreciate your concerns and actions on behalf of chronically ill Lyme patients.

I am writing to you today because we desperately need help. We reviewed the new, and I may add- disastrous- Lyme disease guideline draft written by the Infectious Diseases Society of America's (IDSA) and discovered in spite of all the new science and clinical experience we now have access to, and after thirty long years of sick patients begging for adequate treatment, **nothing** in the guidelines has changed in the way of diagnostics or treatment protocols for the patients or the health care providers who treat them.

The recommendations in the supposedly "new" 2019 guidelines are the same as were published in the IDSA's 2000, and again in their 2006 Lyme disease guidelines. The authors continue to advise against using more sensitive diagnostic tests already on the market, and promote the same inaccurate tests that miss 74.9% of those infected. (Patents involved. $$)

The same short course of inexpensive antibiotics that failed to cure the majority of patients has also not changed. It still consists of **one dose** of doxycycline if it can be administered within the first 72 hours of a tick bite, but only in an endemic area where the tick was found engorged, and only if its species is known (Ixodes). That unsupported theory has been disproven by multiple studies time and again and is still being promoted by the IDSA.

A major problem blocking access to treatment is that when health care professionals don't adhere to these restrictive, insurance-friendly IDSA guidelines they risk being charged by the Maryland Board of Physicians, and many have been. This is not only a Maryland problem that is used by the IDSA to frighten medical professionals from doing right by their patients, but an ongoing, nationwide travesty that unjustly and severely punishes both Lyme doctors and their patients.

To Note- Over 112 health care professionals, and we don't have many, specializing in the treatment of Lyme disease have been targeted, investigated and officially charged with violations related to what the IDSA refers to as the "over diagnosing or over treating" of Lyme disease. Some professionals have been investigated and charged multiple times at great personal expense. Most recently, complaints that generate these investigations have been refocused in an attempt to draw attention away from these underhanded and obvious attacks, and charges are now often based on non-Lyme related offenses, such as record keeping errors, prescribing pain medications to treat chronically ill patients that doctors are not allowed to treat otherwise, and such. And no, the Board is not interested in working toward a solution, and I have little faith that Med-Chi will support the necessary changes.

Therefore, if doctors don't stick their necks out to help their patients, and instead follow the IDSA guidelines, we will have more and more Lyme patients who will continue to suffer, become chronically ill, disabled and/or die on our watch. This situation is simply outrageous. We can not allow the Board of Physicians, insurers and uneducated doctors to restrict our treatment options, or insist everyone follow a cookie-cutter approach to treating any disease, least they be punished. We need to open the doors to healing!

According to a handful of IDSA Lyme disease guideline authors who have a personal and financial stake in the outcome, there still is no such thing as chronic Lyme disease. For example- the new IDSA guidelines state- “The term ‘chronic Lyme disease’ as currently used lacks an accepted definition for either clinical use or scientific study, and it has not been widely accepted in the medical or scientific community.” This simply is not true. Linked here is the official definition of chronic Lyme disease, written by Stricker, et. al., published in the American Journal of Infectious Diseases.

The IDSA also continues to falsely state that sick (chronically ill) patients simply have “medically unexplained symptoms” (pg. 65) and as a result require no treatment. Granted, this is slightly different than how they explained away ‘chronic Lyme disease’ in their previous set of guidelines when they stated chronically ill patients simply have the “aches and pains of daily living”. We all know that is crazy talk. Lyme patients are sick and in pain.

We must allow health care providers to treat patients as individuals and not tie their hands, especially when the justification for tying their hands is based on treatment guidelines proven to be terribly inaccurate and unsuccessful to boot. Example- After a lengthy review, the national Institutes of Medicine (IOM) found that the 2006 IDSA Lyme disease guidelines were so flawed they used them as THE example of how NOT to write guidelines.

On May 1, 2008, the Attorney General of Connecticut (now US Senator) Richard Blumenthal stated: "The IDSA's 2006 Lyme disease guideline panel undercut its credibility by allowing individuals with financial interests -- in drug companies, Lyme disease diagnostic tests, patents and consulting arrangements with insurance companies -- to exclude divergent medical evidence and opinion.” Some of these discredited authors are also on the 2019 guidelines. They’ve declared a war on patients and doctors treating them. (See attached.)

The situation has become so desperate that 25 living patients and the families of 3 Lyme patients who have died, filed a RICO legal action against the IDSA, nine insurance companies and a number of individual IDSA Lyme disease guideline panelists, three who are authors of the latest 2019 Lyme guidelines. The case, as most legal cases do, is moving forward slowly; however, even if we have a win it still won’t protect our doctors.

More documentation is attached. I encourage you to read it when able and thank you for doing so. It’s an eye-opener and there is plenty more if you are interested. In the meantime, please do not just support, but actively fight for the passage of SB103 so we can get some relief. You won’t regret it.

If you have any questions please let me know. And don’t forget, do a tick check!

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PS- I can no longer attend hearings in person. I am totally disabled and mostly bed bound or house bound. But, I will watch the hearing so I can report back to others.

The 2019 Lyme Disease Guidelines Recommend Against

AGAINST- Treating morphologic variants of Borrelia (aka cyst forms, L-forms, round bodies, biofilms) often detected in people with chronic Lyme disease. (pg. 14)

AGAINST- Testing ticks to determine what infections they may carry. (pg. 19)

AGAINST- Testing or treating people bitten by ticks that are asymptomatic, even if they have positive Lyme tests. (pg. 20)

AGAINST- Prophylactic treatment unless a tick is attached and engorged for more than 36 hours and other specific criteria are also met (pg. 21), and then only ONE DOSE of an antibiotic is recommended (200 mg of Doxycycline). (pg. 21)

AGAINST- Treating patients with an EM (Lyme) rash that isn't a "typical" bulls-eye rash. Must use a "wait and see" approach (their words). (pg. 21)

AGAINST- Using a more sensitive Western Blot test. Instead they recommend using two of the cheaper EIA tests together. (pg. 26)

AGAINST- Treating Lyme with more than 10 days of doxycycline or a 14 day course of amoxicillin. (pg. 30) They also recommend performing studies to determine if even shorter courses of doxycycline could be prescribed. (pg. 31)

AGAINST- People being treated if they have an EM (Lyme) rash if the tick wasn't of a certain species (Ixodes). (pg. 31)

AGAINST- Using the more sensitive PCR tests in cerebrospinal fluid. (pg. 33) To Note- A European study showed only a 34-58% sensitivity, depending what test was used, and another study (by one of the guideline authors, Steere) showed only 18-25% sensitivity, with numerous headaches and spinal fluid leakages reported as side effects.

AGAINST- Patient's blood being tested for Lyme if neurological symptoms are present, and instead testing the cerebral spinal fluid (CSF). To note- Johns Hopkins study of various Lyme tests indicated of 3 CSF specimens provided- one grew Borrelia spirochetes, one did not and the other they claimed was contaminated and couldn't be analyzed. (pg.9) In another study the guideline authors admit only 5% of Lyme patients tested positive using PCR on CSF. (pg. 34)

AGAINST- Testing any ALS, relapsing MS, Parkinson's disease, dementia, cognitive decline or new onset seizure patients for Lyme disease. (pg. 36)

AGAINST- Testing patient's with neurological symptoms that aren't on the abbreviated list the IDSA authors produced for Lyme disease. (pg. 36)

AGAINST- Testing patients with white matter abnormalities that appear on MRIs for Lyme disease. (pg. 36)

AGAINST- Testing adults or children with psychiatric conditions for Lyme disease. (pg. 38) To Note- Lyme patients experiencing psychiatric and neuropsychiatric conditions has been long known and is well established. Examples- Suicide and Lyme and Associated Diseases - Late-Stage Neuropsychiatric Lyme Borreliosis Based Upon An Analysis of 100 Patients – Aggressiveness, Violence, Homicidality, Homicide and Lyme Disease – Late-stage Neuropsychiatric Lyme Borreliosis

AGAINST- Treating heart symptoms (Lyme carditis) with different antibiotics that are currently used for treating the milder, early flu-like symptoms. (pg.47)

AGAINST- Testing or treating patients with chronic cardiomyopathy of unknown cause. (pg. 48)

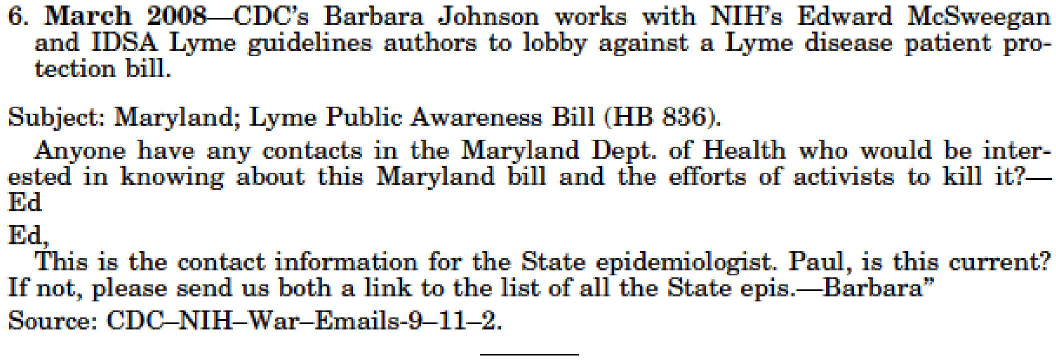
AGAINST- Using PCR tests on synovial fluids when testing for Lyme arthritis. (pg. 50) To Note- PCR testing detected a new Lyme genospecies (*Borrelia mayonni*) that would have otherwise been missed. Amongst other reasons to not discount a PCR test, improvements are being made in multiple tick borne disease PCR assays.

AGAINST- Treating patients with antibiotics who still have symptoms after completing the short course of antibiotics promoted in the guidelines. (pg. 61)

AGAINST- Treating patients with different antibiotics or extended durations when they have the late acrodermatitis chronica atrophicans (ACA) skin manifestations which indicates they continue to have active infection. In other words, they prescribe the same treatment for those in the late stages as was prescribed for them in the early stages that failed to cure them. (pg. 66)

The IDSA guidelines continue to deny the existence of chronic Lyme disease and falsely states that it doesn't even have a definition. Chronic Lyme Disease Definition- https://thescipub.com/pdf/10.3844/ajidsp.2018.1.44

FOIA Document



6. **March 2008**—CDC's Barbara Johnson works with NIH's Edward McSweegan and IDSA Lyme guidelines authors to lobby against a Lyme disease patient protection bill.

Subject: Maryland; Lyme Public Awareness Bill (HB 836).

Anyone have any contacts in the Maryland Dept. of Health who would be interested in knowing about this Maryland bill and the efforts of activists to kill it?—Ed

Ed,

This is the contact information for the State epidemiologist. Paul, is this current? If not, please send us both a link to the list of all the State epis.—Barbara"

Source: CDC–NIH–War–Emails-9–11–2.

Source- https://www.govinfo.gov/content/pkg/CHRG-112shrg75786/pdf/CHRG-112shrg75786.pdf

"WAR" Declared on Lyme Patients, Volunteer Advocates & Lyme Doctors

FOIA Document- Email from NIH employee and coauthor on multiple studies with IDSA Lyme guideline authors, Edward McSweegan. To Dr. Susan O'Connell in the UK, 2/2/2007.

"If outer space is the militaries ultimate "high ground", then cyberspace is the high ground in an information war. And what we have here is a war. ... It's time to start shooting back."
https://drive.google.com/file/d/0BySm7nJtGqM7UENsTDFiQUU0T1k/view

"Whatever course we choose, it's going to be a long struggle. The Lymees and their parasitic LLMDs [Lyme treating MD's] have been at this for a very long time. Their tireless legislative and letter-writing efforts are, to me, reminiscent of the tactics of Intelligent Design proponents…"
https://drive.google.com/file/d/0BySm7nJtGqM7bDJPOVJORGpocnM/view

NIH employee, IDSA guideline supporter and member of the International- Threats & Uncivil Actions Against Lyme Patients
https://sites.google.com/site/edwardmcsweegan/letters-to-patients/mm-drymon
https://sites.google.com/site/edwardmcsweegan/hit-list?authuser=0

Selected Quotes- IDSA Lyme Ad Hoc Committee Member- Attacks on Lyme Patients, Labs, Doctors & Legislators
https://sites.google.com/site/edwardmcsweegan/quotes

Additional Materials- pg. 44- https://www.govinfo.gov/content/pkg/CHRG-112shrg75786/pdf/CHRG-112shrg75786.pdf