



TESTIMONY

**Lyme and Tick-Borne Diseases
New York State Senate Task Force on Lyme and Tick Borne Diseases and
The Senate Standing Committee on Health
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"In the fullness of time, the mainstream handling of chronic Lyme disease will be viewed as one of the most shameful episodes in the history of medicine..."

- Kenneth B. Liegner, MD

Senator Serino, Senator Hannon, Members of the Task Force and Health Committee -- thank you for the opportunity to testify today.

My name is Christina Fisk, and I am the President of the Lyme Action Network, a seven-year-old organization working primarily in the areas of public and patient education and advocacy, including state and national policy reform.

Before I begin my remarks, I'd like to note that over the past several weeks, tick-borne diseases have claimed the lives of several people in our region, and I'd like to recognize them and their families. The need for leadership and action on this problem is urgent, and we thank Senators Serino and Hannon for convening this hearing to direct additional focus to this multidimensional challenge.

Today I would like to bring to your attention behaviors and practices occurring in this state --all day, every day-- that deny one solitary population of medically afflicted individuals their rights as patients and human beings -- practices which are so pervasive they have become normalized and assimilated into daily medical routine, and which, when challenged, are vigorously and wrongfully defended.

Today I'm speaking on the issue of patients' rights, particularly as they apply to Lyme disease patients.

Lyme disease is one of about 25 known conditions where there is more than one treatment option available to the patient. Breast cancer and prostate cancer are other familiar examples where you have choices about your treatment. Physicians access information about treatment options through the National Guideline Clearinghouse (NGC) , which is a database of peer-reviewed treatment protocols maintained by an agency (Agency for Healthcare Research and Quality) within the U.S. Dept of Health and Human Services.

Guidelines posted on the NGC must meet the rigorous standards of being peer-reviewed, evidence based, and developed for trustworthiness and transparency, as required by the National Academy of Medicine. These are referred to as GRADE standards. (Grading of Recommendations Assessment, Development and Evaluation)

In other words, the treatment guidelines posted on the NGC are legitimate and can be trusted.

We all take it for granted that if there are choices to be made about our care, we'll be properly informed, advised, and consulted, and that is probably a safe bet, UNLESS you are a Lyme patient. If you happened to get bitten by a tick this system DOES NOT APPLY TO YOU! As a matter of fact, it applies to just about everybody EXCEPT you!

Although Lyme disease can be treated by more than one set of guidelines, the predominant custom of the medical professionals in this country, including those in New York, is to ignore the patient's rights to be accurately informed about his disease and treatment options, and offer only one treatment construct. This CDC-favored construct, has hardly changed in 40 years, is based upon badly flawed original science from the mid 70's, has been deleterious to countless patients, and has been actively contested and criticized for its failures since the 1980's. These old guidelines were not developed to the GRADE standards as now required by the National Academy of Medicine, and, in fact, were delisted from the NGC in 2016 for being out of date and out of compliance. While they are currently under revision, physicians and medical organizations can still use them, and they do, to the near-complete exclusion of the more current treatment guidelines posted in 2015 that are based on current and independent research and not only meet, but exceed internationally accepted standards.

If you are bitten by a tick, nearly no first line medical professional will tell you that that you have a choice of treatment options, one old and out of date and another more current.

You won't be told that a growing number of physicians around the globe have been turning to the newer guidelines in the face of the frequent and often catastrophic failures of the old guidelines.

No one will explain to you that the guidelines under which you will be treated often fail the patient from their first diagnostic visit, where misinformation of astonishing scope appears to be the norm, not the exception.

For example, I recently heard from two patients who were told that their positive blood tests were "false positives" (the chances for which are very slight) and told that they were fine, despite the CDC's recognition of positive serology as confirmation of Borrelia infection. They got sicker until they finally were properly diagnosed.

I also heard from the mother of a 2-year old who was bitten by a tick, developed rashes, swollen joints, extreme fatigue, and a fever, was initially diagnosed with Lyme disease, and began treatment and was responsive, and then was removed from treatment when his blood-test came back negative. This is a blood test that is wrong 50% of the time. The doctor believed the blood test was definitive, told his mother those bulls-eye rashes on your baby are just allergies, and discontinued treatment. This little guy's health deteriorated precipitously until he was finally diagnosed with Lyme by another doctor weeks later and restarted on antibiotics.

A third example is a very difficult story of a young man with confirmed late-stage neurological Lyme disease, committed to a psychiatric institution. Although his family is requesting treatment under the new guidelines, their requests have been denied. He receives no treatment for Lyme disease and he is deteriorating.

If you get bitten by a tick and treatment is prescribed, no one will mention that the old guidelines recommend less treatment than the newer guidelines, sometimes only one dose -- and that insufficient treatment is frequently implicated in longer-term illness in many patients.

Nobody will mention any of that to you. You will be given one choice (often accompanied by dangerous misinformation) -- and you can take it or leave it. If you know enough to request the newer guidelines, you will be denied.

The antiquated guidelines are the ones taught in medical schools, served up with a heavy dose of bias against the newer and competitive guidelines. Incredibly and unfortunately, taxpayer dollars are used to perpetuate biased information in the development of public education materials and in the support of professional continuing medical education that only represents the old construct. State-funded medical institutions, psychiatric facilities, correctional institutions, and other state entities adhere to only one badly flawed point of view. These old guidelines have

such a tight grip on mainstream medicine that they take on the affect of a religious conviction rather than a field supposedly informed by scientific fact.

Patients have a right to accurate and honest information, and they have a right to chose their treatment option. What's happening hundreds of times a day is institutionalized discrimination against one group of disabled people. The reasons behind this are well known and unfortunately we don't have the time to discuss them now, but at the end of the day, they don't matter to this charge.

Our claim today is that Lyme patients, uniquely, unlike any other category of people temporarily or permanently disabled, are victims of a pervasive and broad pattern of discrimination . These discriminations are often against vulnerable patient groups -- women and children (children make up the highest percentage of new cases every year), the impoverished, the elderly, and others.

To add insult to injury, their insurance, which only covers limited treatment under the old guidelines, usually terminates after a few weeks, because they are declared "cured" by their physicians after a short course of treatment, as per the old guidelines, and they are left to fend for themselves against a highly complex, and very destructive bacterial infection.

These abuses are in violation of the Americans with Disabilities Act of 1990 and the American Medical Association's Code of Ethics.

They also offend the fundamental tenets of the World Health Organization, which has declared *that "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition."*

Better health is attainable if people are allowed to access better treatment.

I come today not to ask you to take on a 35 year old battle between professional medical societies, but rather to take an active stand on behalf of the people who have been relentlessly victimized and marginalized by this controversy. We ask that you initiate a course of action that will result in tick-borne disease patients having full access not only to complete and correct information about their

illnesses, like every other group, but also have reasonable access to the treatment of their choosing, and reasonable parity in insurance coverage.

We urge you to inspire New York State to take a national leadership role to end "business as usual" regarding the discrimination against Lyme patients and their health care providers, and find equitable solutions to the unjust relationships these patients have with their insurance companies. Uniquely, we're not asking for anything special. We're just asking that Lyme patients receive the same rights and considerations as every other person with a health challenge.

By changing the mindset from that of an intractable medical issue to one of improving the system based upon the restoration of patient' rights, positive effects will result and opportunities will emerge:

- individuals who are diagnosed and treated early and adequately are unlikely to join the ranks of the chronically ill.
- individuals who regain their health -- even to some degree -- can retain their jobs, and maintain financial independence.
- insurance companies that embrace early intervention can spend pennies to sufficiently address Lyme disease early in the course of disease saving fortunes on later testing and treatment for the myriad complications, such as cardiac and neurological problems, that often occur in later disease.
- demand for updated treatment protocols is high and if allowed, could support new medical/treatment enterprises.
- New York can encourage the process through investment in regional treatment centers similar to the Spaulding Center in Boston, which now has a one-year waiting list.

There is much more to talk about on this topic and the positive outcomes that will flow from reform. We are more than willing to participate in any discussions to help move this situation along to a more just and productive end.

References

National Guideline Clearinghouse™ (NGC)

Mission

NGC is a database and Web site for information on evidence-based clinical practice guidelines. NGC is sponsored by AHRQ to promote widespread access to clinical practice guidelines; in fact, it is the "go to place" to find guidelines. It was originally created by AHRQ in partnership with the American Medical Association and the American Association of Health Plans (now America's Health Insurance Plans [AHIP]).

The NGC mission is to provide an accessible mechanism for obtaining detailed information on clinical practice guidelines, and to further their dissemination, implementation, and use in order to inform health care decisions.

Constitution of the World Health Organization: Principles

- Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.
- The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.
- The health of all peoples is fundamental to the attainment of peace and security and is dependent on the fullest co-operation of individuals and States.
- The achievement of any State in the promotion and protection of health is of value to all.
- Unequal development in different countries in the promotion of health and control of diseases, especially communicable disease, is a common danger.
- Healthy development of the child is of basic importance; the ability to live harmoniously in a changing total environment is essential to such development.
- The extension to all peoples of the benefits of medical, psychological and related knowledge is essential to the fullest attainment of health.
- Informed opinion and active co-operation on the part of the public are of the utmost importance in the improvement of the health of the people.
- Governments have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures.

AMA CODE OF MEDICAL ETHICS AMA PRINCIPLES OF MEDICAL ETHICS* Preamble

Principles of medical ethics

I. A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights.

II. A physician shall uphold the standards of professionalism, be honest in all professional interactions, and strive to report physicians deficient in character or competence, or engaging in fraud or deception, to appropriate entities.

III. A physician shall respect the law and also recognize a responsibility to seek changes in those requirements which are contrary to the best interests of the patient.

IV. A physician shall respect the rights of patients, colleagues, and other health professionals, and shall safeguard patient confidences and privacy within the constraints of the law.

V. A physician shall continue to study, apply, and advance scientific knowledge, maintain a commitment to medical education, make relevant information available to patients, colleagues, and the public, obtain consultation, and use the talents of other health professionals when indicated.

VI. A physician shall, in the provision of appropriate patient care, except in emergencies, be free to choose whom to serve, with whom to associate, and the environment in which to provide medical care.

VII. A physician shall recognize a responsibility to participate in activities contributing to the improvement of the community and the betterment of public health.

VIII. A physician shall, while caring for a patient, regard responsibility to the patient as paramount.

IX. A physician shall support access to medical care for all people.

The Americans with Disabilities Act of 1990

The Americans with Disabilities Act of 1990 provides for two key rights that are being routinely violated in New York State:

A. Individuals with the condition referred to as Chronic Lyme, Post Lyme Treatment Syndrome, Late Stage Lyme disease, Lyme Complex, Multiple Systemic Inflammatory Disease, and other names are being denied appropriate attention and acknowledgement by the NYS DOH and other New York agencies.

Sec. 12132. Discrimination

Subject to the provisions of this subchapter, no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.

B. Titles I and III of the ADA each prohibit not just discrimination against the disabled, but also against discrimination “to an individual or entity because of the known disability of an individual with whom the individual or entity is known to have a relationship or association”. Title II does not contain such language, however, the Department of Justice adopted this “association” protection in Title II’s implementing regulation found at 28 CFR 35.130(g):

“A public entity shall not exclude or otherwise deny equal services, programs , or activities to an individual or entity because of the known disability of an individual with whom the individual or entity is known to have a relationship or association.”

The validity of the association clause in the regulations promulgated under Title II was upheld in a recent Second Circuit, Innovative Health System v. City of White Plains, 117 F.3d 37 (2d Cir. 1997). Moreover, the purpose of the association provision is to protect health care providers:

This provision was intended to ensure that entities such as health care providers, employees of social services agencies, and others who provide professional services to persons with disabilities are not subjected to discrimination because of their professional association with persons with disabilities.

(Excerpted from *Roadmap to Reform -- Recommendations for Developing Public Policy Responses to the Challenges of Tick-Borne Diseases*, Christina T. Fisk, Holly Ahern, Lyme Action Network. 2014)