



The National Capital Lyme and Tick-Borne Disease Association

Offering Education and Support to those suffering from Lyme and tick-borne diseases

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March 6, 2013

Via e-mail

The Honorable Bob McDonnell
Governor, Commonwealth of Virginia
Office of the Governor
Patrick Henry Building, 3rd Floor
1111 East Broad Street
Richmond, Virginia 23219

Re: HB 1933 Lyme Disease Testing; Written Information To Patient

Dear Governor McDonnell:

I write again on behalf of our members, our chapters, and all the Lyme sufferers across the Commonwealth. For over 14 years NatCapLyme has offered support and education about Lyme and Tick-borne diseases to patients and their family members and raised awareness about the increasing number of Lyme disease cases in the Commonwealth of Virginia. Our association has eleven chapters located throughout the state with a membership of over 3,000, reflecting the growing problem of Lyme in the region. I represented our members as an appointed member of your Governor's Task Force on Lyme Disease in 2011.

On February 25, I sent you an e-mail message seeking your support for HB1933, the Lyme Disease Testing Information Act. A copy of that message, in letter form, is attached. As recognized by the Medical Society of Virginia ("MSV") on its website, the House and the Senate passed this legislation with votes that "defied party and regional lines." It was strongly supported by Republicans and Democrats from both urban and rural areas of the Commonwealth. Both chambers concluded that Lyme disease has spread so rapidly and aggressively, and the tests for recognizing it are so inaccurate, that this legislation is needed to assist both physician and patient to understand and interpret the facts together. I am also pleased to report that the Loudoun County Lyme Disease Task Force has voted to endorse this legislation.

Many physicians do not communicate Lyme test reliability information to their patients even though the qualification appears on every Lyme test lab report they get. This very real problem is attested to by more than 8,200 messages sent to Virginia senators and delegates supporting this legislation and approximately 600 messages sent to you urging you to sign this bill without modification. Many of the letters contain moving personal stories. They tell how

lives could have been vastly improved and of the enormous medical costs they might have avoided had only their physician provided this information. Several Senators and Delegates rose to speak for the bill and shared their own personal stories, as I detailed in the attached letter.

As expressed by Senator Black on the Senate floor, HB 1933 already contains compromise language proposed by representatives of the Medical Society of Virginia. The Society later reneged on that compromise and fought the bill in both houses of the legislature. Having lost its battle in the General Assembly, the MSV has now turned to you for a veto. The MSV claims the veto is justified for a variety of reasons, *each of which is insufficient to justify your veto.*

MSV argues that to require a health care provider to provide a patient the written notice about the test accuracy affronts the free market system, encourages governmental red tape and will impose unjustified mandates on the private enterprise system. They also complain that this will impact staff time and resources, interfering with the physicians' right to private enterprise.

As patient advocates, we recognize that all physicians must govern their medical practice with a degree of business acumen. They cannot help patients if they are not also financially successful. *But medicine remains first and foremost a profession.* Information necessary for the joint decisions physicians and patients must make cannot be withheld simply because it takes time to convey. How best to interpret and utilize test results must be dictated by professional, rather than business, considerations. To claim otherwise is shocking. Withholding that vital information because it may take a moment to hand to a patient a disclosure statement about their lab result, or that the patient may ask the physician pertinent questions, is not a reason to withhold that information and only disserves physicians by reinforcing the impression that many doctors bring an imperial demeanor to their work. As recognized in a March 5, 2013 *Washington Post* article on the problem of physician rage, a 2008 Joint Commission studying intimidating and disruptive behaviors in health care identified refusal to answer patient questions as a critical problem that erodes professionalism and creates an unhealthy and hostile environment. It further found that studies link patient complaints about such unprofessional, disruptive behaviors to malpractice risk.

Contrary to MSV's assertions, experience demonstrates that, although some physicians understand and convey the limitations of the current tests, the majority of Virginia physicians do not. In May 2012, then-Virginia Department of Health Commissioner Karen Remley issued a letter to *all doctors in Virginia* advising them that the Lyme test is problematic and encouraging them all to rely on a clinical diagnoses for Lyme and tick-borne disease. Notwithstanding that letter, many patients continued to report that their Virginia doctors advise that a negative test rules out Lyme disease. That past educational efforts have failed is underscored by the admission of doctors who appeared at legislative committee meetings and admitted that they were unaware of Dr. Remley's letter. Clearly, past efforts to communicate information through less direct means have failed. It is now time to act. This bill will save untold suffering by patients who may never learn the truth about their tests without its benefit.

The MSV also argues that the statute fails to appreciate the importance of "evidence-based medicine" and affronts the sanctity of the physician-patient relationship. However, the

evidence is strong that the FDA-approved blood tests for Lyme Disease are horribly inaccurate. If, as MSV suggests, we are to follow the evidence, then the evidence strongly supports HB1933.

Further, rather than undermine it, the physician-patient relationship is bolstered by this law. It supports providing a simple, clear statement about the efficacy of the test, just as the lab provided it to the physician on the actual lab result, so that it can be discussed *inside* that relationship. The MSV proposed to insert this information somewhere on the Virginia Department of Health website, along with other educational resources. Not only is there no commitment as to what information will be provided, or where it would appear on the department's website, it completely ignores the reality that a patient who is advised that a negative test result rules out Lyme disease would have no reason to search for test information on the VDH website.

The MSV position also ignores the very real problem in America and in Virginia of the so-called digital-divide. Access to the internet is still highly dependent upon socio-economic status and location. The digital divide has been officially recognized by the Federal Communications Commission and this month, in an editorial, the rural Highland County Virginia newspaper, the *Highland Recorder*, stated that relying only on the internet "discriminates against citizens who do not use computers, don't have access to the internet, or don't have the time and resources required to hunt down notices on line through a government system. It puts a burden of digging on others. That's not where it belongs."

Moreover, the MSV approach is actually more dangerous to the physician-patient relationship. It requires the patient to go "digging" for information *after meeting with the physician*. This places the patient in the uncomfortable position of challenging a doctor with after-acquired information following the physician-patient discussion. Patients believe it far better to place that information where it can be discussed inside the confidential context of the physician-patient relationship, where it belongs.

The MSV's final argument is that providing information to the patient that the test is unreliable may encourage the patient to demand antibiotic treatment, even if there is no indication that the medication should be prescribed. The MSV's argument assumes that one of its medically-licensed members would knowingly prescribe an excessive amount of antibiotics when that licensed physician did not believe it to be appropriate, simply because of patient pressure. There is no evidence to support this conclusion and to assume that would happen is demeaning to its own members. I wish to make clear that no patient organization has ever encouraged mandatory antibiotics treatment when not indicated and this bill would do no such thing.

As I mentioned above, I served on your *Governor's Task Force on Lyme Disease*. The Task Force *Final Report*, unanimously adopted on June 30, 2011, sent you several important conclusions pertinent to this legislation. Among them were:


- Lyme and other tick-borne diseases are present in every region of Virginia.

- It is critical to raise awareness in the medical community about Lyme and other tick-borne diseases.
- There is no serological test that can “rule out” Lyme disease.
- Members of Virginia’s medical community inaccurately believed that serology alone can “rule out” Lyme disease.
- Some members of the Virginia medical community have refused to consider a diagnosis of Lyme-related illness on the ground that “we do not have Lyme in Virginia” or in this “part of Virginia.”

When all of the evidence is considered, and all the arguments judged, we are confident that you will realize the importance of this legislation and its ability to contribute significantly to the health and welfare of the citizens of the Commonwealth. It is indeed a small measure – not a major step – but one that is extremely important and can do enormous good.

On behalf of thousands of Virginia Lyme patients who wish a better outcome for those yet to contract the disease, I ask respectfully that you sign this legislation into law.

Sincerely,

A handwritten signature in blue ink, appearing to read "Monte Skall", with a long horizontal flourish extending to the right.

Monte Skall
Executive Director