

The National Capital Lyme and Tick-Borne Disease Association

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

P.O. Box 8211 • McLean, VA 22106-8211• Phone & Fax 703-821-8833 natcaplyme@natcaplyme.org

February 25, 2013

Via: e-mail and facsimile: (804) 371-6351

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

Dear Governor McDonnell:

On behalf of our members, our chapters, and all the Lyme sufferers across the Commonwealth we ask you to support HB 1933, the Lyme Disease Testing Information Act that has been passed by the Virginia Senate and House of Delegates and sent to you for signature. I write this letter to let you know that this bill is supported by thousands of Lyme disease patients, their friends and family throughout the Commonwealth, all of whom are praying that you will sign this bill in the form it has been sent to you. This bill produced over 8,200 messages from Virginia constituents urging their senators and delegates to vote for the bill language that will reach your desk.

The Lyme Disease Testing Information Act will ensure that Virginia residents are adequately educated and informed of the limitations in the existing serologic tests used to detect Lyme disease in its early stages. Standard lab tests often result in false negative and false positive results, and if done too early, may not produce enough antibodies to be considered positive because the immune response requires time to develop antibodies resulting in many Virginia residents being misdiagnosed or receiving improper treatment. Results rendered by commercial clinical laboratories bear disclaimers noting that the results may yield false results and the need for additional testing. Our experience is strong that that even though physicians get the information on patient's lab reports, many doctors still report to patients that a negative test means they do not have Lyme disease. HB 1933 insures that the patient is adequately informed of the potential of error in laboratory testing with an advisory.

We know there was opposition to the bill. However, the arguments provided in the Senate and House hearings by Lyme disease patient advocates were fully responsive to the bill's opponents. Moreover, the bill only assures that patients are provided information critical to

making an informed health care decision. The failure to communicate this information is inconsistent with expectations for the physician-patient relationship.

Several members of the legislature rose to speak on behalf of the bill and conveyed personal stories of their own families who would have benefited by the knowledge provided by this bill to Lyme patients. In her comments, Senator Janet Howell indicated that Lyme disease was verging on a plague in her district, that there are whole families in which every member of the home has the disease, and that nobody seems to know how to prevent this is a very complicated disease. Delegate James Edmunds stated that he believes in 1988 his father died from untreated Lyme disease. Senator Thomas Garrett told a compassionate story about his nephew afflicted with tick-borne disease. Please view those videos, available on our website at www.natcaplyme.org or www.youtube.com/natcaplyme.

We know that you have been very concerned about Lyme disease, addressing the problem in your gubernatorial campaign and by your establishing the Governor's task force on Lyme disease. I had the privilege to sit on that task force. We heard from many chronic Lyme patients who testified that their lives would be different today if only they had been correctly informed about testing limitations. HB 1933 could save lives and life quality, save thousands of dollars of avoidable medical costs, and provide the physician with an easy, inexpensive and reliable way to provide patients with the information they need to make informed decisions about their own health care. Please support all those Lyme patients who supported you, by signing this bill without alteration and in the form sent to you in HB 1933.

Sincerely,

Monte Skall

Executive Director