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STATE LYME DISEASE STUDIES

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You asked for a summary of the Governor's Task Force on Lyme Disease in Virginia, including (1) how the task force was formed, (2) the task force members, and (3) what the task force recommended. You also asked about similar initiatives in other states.

SUMMARY

In 2010, Virginia's governor and Health and Human Resources secretary convened a Lyme disease task force, in response to growing cases of Lyme disease and similar illnesses in the state. The task force consisted of stakeholders and experts from the public and private sectors. It made a number of recommendations involving how the state, localities, medical community, and public should approach Lyme disease and related illnesses.

Other states have dealt with the growing Lyme disease problem in a variety of ways. For example, the Maryland Department of Health and Mental Hygiene formed a subcommittee on Lyme disease, which issued a 2007 report examining the problem of Lyme disease in the state and suggesting specific recommendations for state agencies, many of which have since been implemented. In Massachusetts, the House Committee on Post Audit and Oversight issued a similar report in 2011, recommending creation of a special commission on Lyme disease. The state's FY 12 budget creates such a commission.

Several other states have proposed legislation calling for the creation of a Lyme disease task force, although none have yet passed. In Connecticut, the Public Health Committee favorably reported a bill (HB 5335) in March 2012 that would create a task force to study Lyme disease testing.

Below, we summarize the Virginia task force's report, which is also attached. We also summarize the Maryland and Massachusetts reports.

More information about Lyme disease is available on the Centers for Disease Control and Prevention's (CDC) website: <http://www.cdc.gov/lyme/>. The website includes information on several topics, such as Lyme disease prevention, diagnosis, and treatment; case statistics; and links to other resources.

VIRGINIA GOVERNOR'S TASK FORCE ON LYME DISEASE

Overview

In October 2010, Virginia Governor Bob McDonnell and Secretary of Health and Human Resources William Hazel, Jr. convened a task force to study and make recommendations in the following areas related to Lyme disease: (1) diagnosis, (2) treatment, (3) prevention, (4) impact on children, and (5) public education. The task force unanimously adopted its final report on June 30, 2011.

In December 2011, Governor McDonnell introduced his proposed budget for the 2012-2014 biennium, which included a general fund appropriation of \$112,500 per year for FY 13 and FY 14 to implement the task force's recommendations. The final Virginia budget is still being negotiated.

The task force members, listed in Table 1, included representatives from government, health professions, academia, and Lyme disease organizations.

Table 1: Virginia Lyme Disease Task Force Members

Name	Title/ Affiliation
Michael Farris (Task Force Chairperson)	Chancellor, Patrick Henry College
Heather Applegate, Ph.D.	Child psychologist; supervisor, Diagnostic and Prevention Services, Loudoun County Public Schools, and private clinician
Dianne L. Reynolds-Cane, MD	Director, Virginia Department of Health Professions
Douglas W. Domenech	Virginia Secretary of Natural Resources
Bob Duncan	Executive Director, Virginia Department of Game and Inland Fisheries
Keri Hall, MD, MS	State Epidemiologist, Virginia Department of Health
William A. Hazel, Jr., MD	Virginia Secretary of Health and Human Resources
Kathy Meyer	Co-organizer of Parents of Children with Lyme Support Network, Northern Virginia
Samuel Shor, MD, FACP	Associate Clinical Professor, George Washington University Health Care Sciences, and private practice, Internal Medicine, Reston, VA
Monte Skall	Executive Director, National Capital Lyme and Tick-Borne Disease Association, Mclean, VA
Lisa Strucko, Pharm.D.	Clinical Pharmacist, Leesburg Pharmacy, Leesburg, VA
Rand Wachsstock, DVM	Veterinarian, Springfield, VA and former instructor in biochemistry at Yale University

The task force held eight hearings (five devoted to state residents impacted by Lyme and other tick-borne diseases and three devoted to particular topics) and heard testimony from a number of residents and experts. Experts appearing at the hearings included, among several others, representatives from the CDC, Infectious Diseases Society of America, International Lyme and Associated Diseases Society, and Virginia Department of Health (VDH).

In its report, the task force noted that it “made every effort to seek a balanced approach in each of the topical areas where there are recognized divergent views. In general, we were able to find willing witnesses representing a variety of viewpoints on such issues” (page 5).

Findings and Recommendations

We summarize the report’s findings and recommendations below. Please note that we do not include all of the task force’s findings and recommendations or all details for those discussed. For example, in some cases, we have combined or condensed recommendations. For a full list of the task force findings and recommendations, see the task force report, attached.

General Observations. Among other findings and observations, the report noted that:

1. Lyme disease and other tick-borne illnesses affect a significant and growing number of residents;
2. more research is needed, as much remains to be understood about these diseases;
3. the public's and the medical community's awareness must be increased;
4. the CDC definition for Lyme disease is for epidemiological purposes only and is not the singular valid basis for diagnosis; and
5. significant improvements in Lyme prevention are possible, but will require cooperation and action of all sectors—governmental, private, business, community, family, and individuals.

General Recommendation. The task force recommended that VDH receive funding to enhance its tick-borne diseases program. Key elements of an effective program include (1) human disease surveillance, (2) tick surveillance and testing, and (3) general public and healthcare provider outreach and education.

The report notes that all of its recommendations for education should include an open and balanced review of the full literature.

Diagnosis. Among other things, the task force made the following findings and recommendations related to diagnosis:

1. clinical diagnosis supported by serology remains the proper method for diagnosing Lyme and related illnesses;
2. no serological test can rule out Lyme disease, the enzyme-linked immunosorbent assay (ELISA) test (a frequently used diagnostic test) may be highly questionable for early localized disease, and in many cases Lyme and related illnesses cannot be adequately diagnosed by serology alone;
3. many patients with Lyme disease may never develop or observe an erythema migrans (EM) rash (a red, expanding rash) and a rash can form in non-traditional patterns;

4. according to lay testimony, some members of the Virginia medical community mistakenly believe that there is no Lyme disease in the state or certain parts of the state;
5. the medical community should be educated on the presence of co-infections;
6. medical providers may need to treat Lyme disease prophylactically when a blacklegged tick is attached, especially if it is engorged, because of the high risk of disease in such cases;
7. there should be increased financial support for clinical studies of Lyme diagnosis and treatment;
8. institutions offering graduate medical degrees should offer comprehensive instruction about Lyme and other tick-borne diseases; and
9. VDH should continue to provide clinicians with information about Lyme and related diseases, and should emphasize the need to keep current on developments related to these diseases.

Treatment. The task force's findings and recommendations related to treatment included the following:

1. typically, a patient is well when symptoms have resolved and he or she feels better, and no serological test can tell a medical provider when a patient has been cured of Lyme disease;
2. there was conflicting testimony on the effectiveness of long-term antibiotics to treat Lyme disease and additional studies are encouraged;
3. the Department of Health Professions should inform licensees that the department does not target clinicians for disciplinary action for their antibiotic choice in managing Lyme disease;
4. lay witnesses expressed displeasure with the medical community's tendency to treat people who were ultimately diagnosed with late stage Lyme disease as needing psychological evaluation or treatment; and

5. lay witnesses stated that long term treatment of Lyme disease is often not covered by insurance and they can spend thousands of dollars per month for treatment, and the Bureau of Insurance should evaluate this issue.

Public Education and Prevention. The task force's findings and recommendations on public education and prevention included the following:

1. the general public and medical community must become fully aware of the risk of Lyme and related illnesses and the severe medical consequences that can arise when they are not promptly diagnosed and treated;
2. the governor and VDH should expand their public education programs to increase emphasis on Lyme disease;
3. the public should be educated on the presence of co-infections;
4. VDH and other state and local agencies should place greater emphasis on public education through modern media;
5. Virginia's approach to Lyme prevention and treatment must involve collaboration between all branches of state government and coordination with local government;
6. the governor should consider convening a task force of state and local officials to create a best practices model for government;
7. Virginia should clearly communicate the expectation that government agencies implement the same safe practices being recommended to the public;
8. the General Assembly may wish to consider amending state law to allow localities to establish tick surveillance and control districts;
9. the governor should establish a working group to develop guidance and potential strategies for localities attempting deer or tick population control and include funding for this in the budget; and
10. public education programs on Lyme prevention should continue to emphasize land-use practices for preventing tick exposure, tick control and acaricides (pesticides that kill ticks), deer control, human practices to limit tick exposure, using appropriate dress

and repellants, showering after being outdoors, evening tick checks, and proper pet practices.

Children. Findings and recommendations related to children included the following:

1. VDH should include in its education materials information about the potential danger of in utero transmission of Lyme disease;
2. VDH should inform the public that children are a high-risk group for contracting Lyme disease;
3. VDH needs to undertake focused campaigns to help educate clinicians about the importance of early Lyme disease recognition;
4. VDH, the Virginia Department of Education (DOE), other agencies, and subject matter experts should collaborate to create a best practices document focused on children with Lyme and related illnesses. Topics to consider include, among others, (a) proper construction of school grounds to exclude deer and avoid unnecessary tick exposure, (b) preparing students appropriately before taking them outdoors for instructional field investigations, and (c) educating teachers and other professionals about Lyme disease, especially the relationship between Lyme and neurological impairment that may result in learning, attention, or memory difficulties;
5. VDH should continue to provide information to school nurses about Lyme and other tick-borne diseases;
6. educators should consider appropriate and sensitive modifications for students with late-stage Lyme disease to maximize their educational progress; and
7. VDH should continue collaborating with the DOE, Virginia Council for Private Education, and home schooling associations to explore developing materials for the science and health education curriculum on preventing these diseases and identifying ticks.

MARYLAND SUBCOMMITTEE REPORT

In 2005, in response to calls for an improved Lyme disease response by patient advocacy groups, Maryland formed a Lyme disease subcommittee to the Department of Health and Mental Hygiene's Vector-Borne Disease Interagency Task Force. The subcommittee consisted of public health and other state agency officials, local public health officials, representatives from patient advocacy and support groups, physicians, and other health care officials. In March 2007, the subcommittee issued a report entitled "Recommendations for the Development of a Strategic Plan for Lyme Disease Prevention and Control in Maryland."

The report explains the history of the disease in Maryland: it became a formally reportable disease in 1989 and the number of reported cases increased from 238 in 1990 to 1,235 in 2005. The subcommittee recommended an integrated public health program to reduce the incidence of Lyme disease and strengthen control measures. This requires (1) cooperation between the public health department, healthcare organizations, and patient support and advocacy groups; (2) improved integration in the public health department; (3) improved research and investigation; (4) increased citizen awareness; and (5) increased research to strengthen prevention and treatment techniques.

The subcommittee reviewed and made recommendations about:

1. surveillance,
2. ecology,
3. public awareness and provider education,
4. diagnosis,
5. treatment, and
6. public policy.

Overall, the subcommittee recommended:

1. enhancements to surveillance for Lyme and other tick-borne illnesses for a more accurate picture of the diseases in Maryland,
2. public education about tick population control and the need for additional research on the effectiveness of certain host control measures,

3. increased information sharing for the public and providers to enhance easy access to current diagnostic and treatment information, and
4. making educational materials and programs available to school-aged children and campers
(<http://sites.google.com/site/marylandlyme/strategic-plan>).

According to state agency officials, most of the specific recommendations in the report were adopted by the state agencies, including updating mandatory reporting requirements and improving reporting procedures.

MASSACHUSETTS REPORT AND COMMISSION

In April 2011, the Massachusetts legislature's House Committee on Post Audit and Oversight released a report entitled "Lyme Disease in Massachusetts: A Public Health Crisis." The report details the disease's impact on the state and the challenges of providing treatment. It makes recommendations for a state-wide response.

The report discusses the causes, symptoms, and treatment of Lyme disease; what individuals can do to prevent infection; and the methods used to survey and report Lyme disease in the state. Confirmed cases increased from 2,461 in 2005 to 4,045 in 2009.

The report details methods to control the spread of Lyme disease, which include the creation of a Lyme disease vaccine and management of the quantity of animals which host ticks and the quantity of ticks themselves. Although the Massachusetts Department of Public Health (MDPH) supports Lyme disease prevention in certain ways, the report states that no funds are specifically appropriated for Lyme disease and there is no guarantee that MDPH will continue its efforts.

The committee concluded that Lyme disease was an increasing problem and the state lacks the capacity and understanding to properly address the situation, due to (1) outdated medical research and information on the proper diagnosis and treatment methods, (2) the lack of sufficient appropriated funds to adequately provide outreach to the medical and education communities as well as the public, and (3) inadequate communication and sharing of information on Lyme disease from stakeholders in order to provide a complete picture of the current situation in Massachusetts.

The committee recommended that:

1. a commission be established to provide better insight into the problem and identify possible solutions;
2. legislation mandating insurance coverage for long-term antibiotic treatment for chronic Lyme disease be enacted, which would ensure that patients are able to access necessary treatment;
3. the state should appropriate funding to MDPH to ensure that more educational outreach is done regarding Lyme disease; and
4. MDPH should look into the possibility of combining tick control efforts with mosquito control efforts
(<http://www.malegislature.gov/committees/187/document/house/h46/lymediseasereport>).

In response to the committee's report, the Massachusetts legislature created a special commission to investigate and study Lyme disease and other tick-borne diseases in the FY 12 budget. The study must include, but not be limited to, a cost-benefit analysis of: (1) conducting a Lyme disease public health clinical screening study in high risk regions; (2) developing educational materials and training resources for detecting signs and symptoms of tick-borne illnesses in school-aged populations, to be used by clinical providers and school health personnel; (3) statewide surveillance and testing for tick-borne diseases in both black-legged deer tick and Lone Star ticks; and (4) educating the medical community about research on all aspects of Lyme disease, both acute and chronic.

The commission is also responsible for investigating the availability of grants and federal funds for the study of Lyme disease and other tick-borne diseases. The commission must report the results of its investigation and study, together with drafts of legislation, if any, necessary to carry its recommendations into effect.

The commission consists of 21 members: six legislators; four state government officials (the commissioners of MDPH and the Division of Health Care Finance and Policy, the director of the State Laboratory Institute, and the State Epidemiologist, or their designees); two Lyme disease patients or family members of patients; a physician specializing in infectious diseases; a member of the International Lyme and Associated Diseases Society; two experts in the treatment or research of Lyme disease; two members of Lyme and other tick-borne diseases organizations representing different regions of the state; and

three members of local boards of health from different Lyme endemic areas of the state (<http://www.malegislature.gov/Budget/CurrentBudget>).

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