Final Report of the Lyme Disease Task Force

A Report to the Governor of Virginia

Lyme Disease Task Force

June 30, 2011

Commonwealth of Virginia

The Governor's Task Force on Lyme Disease

FINAL REPORT

Adopted **Unanimously** on June 30, 2011

Introduction

In response to reports of the growing number of cases of Lyme disease and other tick-borne illnesses and out of a sense of concern for the significant number of Virginians infected with these diseases, Governor Bob McDonnell and Secretary William Hazel convened this task force to study and make recommendations in the following areas:

- Diagnosis
- Treatment
- Prevention
- Impact on Children
- Public Education

The Governor and the Secretary appointed the following persons to serve on the Virginia Task Force on Lyme Disease:

Michael Farris, Chairman, The Governor's Task Force on Lyme Disease; 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, Secretary of Natural Resources, Commonwealth of Virginia

Bob Duncan, Executive Director, Virginia Department of Game and Inland Fisheries, Commonwealth of Virginia

Keri Hall, MD, MS, State Epidemiologist, Virginia Department of Health

William A. Hazel, Jr., MD, Secretary of Health and Human Resources, Commonwealth of Virginia

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 separate hearings with two distinct hearing categories.

There were five separate hearings devoted to citizens of Virginia who had been impacted by Lyme and other tick-borne illnesses. These hearings were held in:

- Virginia Beach
- Richmond
- Roanoke
- Springfield
- Harrisonburg

Over 100 citizens testified at these hearings. We were profoundly impacted by this testimony and thank the citizens for their sacrificial efforts to testify.

A second set of hearings were held devoted to particular topics. At these topical hearings, the bulk of the testimony was from subject matter experts, supplemented by testimonies from citizens that had been asked to focus on the particular issue at hand. The following expert witnesses appeared before our Task Force in these hearings:

Diagnosis & Treatment

Marty Schriefer, MD, Chief of Diagnostic and Reference Laboratory, Centers for Disease Control and Prevention

Daniel Cameron, MD, Past President of International Lyme and Associated Diseases Society, epidemiologist and private practice, Internal Medicine, Mt. Kisco, NY.

Elizabeth L. Maloney, MD, Lyme disease educator and Family Practice physician, Wyoming, MN

Paul G. Auwaerter, MD, representative, Infectious Diseases Society of America

Prevention

Charles S. Apperson, Ph.D., Dept. of Entomology, North Carolina State University

Kerry Clark, MPH, Ph.D. Associate Professor, Epidemiology & Environmental Health, Department of Public Health, University of North Florida

David N. Gaines, Ph.D., Public Health Entomologist, VA Department of Health, Office of Epidemiology

J. Mathews (Mat) Pound, Ph.D., Research Entomologist, USDA-ARS Knipling-Bushland U.S. Livestock Insects Research Service

Nelson Lafon, Deer Project Leader, VA Department of Game and Inland Fisheries

Impact on Children

Leo J. Shea III, Ph.D., neuropsychologist, Neuropsychological Evaluation & Treatment Services, P.C., New York, NY

Carolyn Walsh, MD, private practice, Internal Medicine, Lansdowne, VA

Daniel E. Keim, MD, private practice, Pediatric Infectious Disease, Fairfax and Leesburg, VA

Jennifer Jones, RN, BSN, NCSN, School Nurse, Trinity Christian School, Fairfax, VA

Public Education

Jorge Arias, Ph.D., entomologist and Supervisor, Disease Carrying Insects Program, Fairfax County Department of Health, Fairfax, VA

Robert Bransfield, MD, President, International Lyme and Associated Diseases Society, Associate Director of Psychiatry and Chairman of Psychiatric Quality Assurance, Riverview Medical Center, and private practice, Psychiatry, Red Bank, NJ

Graham Hickling, Ph.D., Research Associate Professor, University of Tennessee, Director of UT Center for Wildlife Health, Knoxville, TN

Wayne Hynes, Ph.D., Professor and Chair of the Department of Biological Sciences at Old Dominion University, Norfolk, VA

Holly Gaff, Ph.D., Assistant Professor in the Department of Biological Sciences at Old Dominion University, affiliated with the Virginia Modeling, Analysis and Simulation Center, Norfolk, VA.

Peter F. Demitry, MD, MPH, former Assistant Surgeon General, United States Air Force, and current President, 4-D Enterprises, Haymarket, VA

The Task Force 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.

We received substantial support from the Virginia Department of Health, Secretary Hazel and the Office of the Secretary of Health and Human Resources for which we offer our deep thanks.

We also received the generous cooperation of a number of public and private organizations, which allowed us to hold our hearings without cost. We thank the following organizations for this valuable contribution:

Patrick Henry College
Regent University
James Madison University
Roanoke Public Schools (Stonewall Jackson Middle School)
Immanuel Bible Church
Fairfax County Board of Supervisors
Loudoun County Board of Supervisors
Virginia Department of Health Professions

We begin our findings with some general observations that should be considered by all to be non-controversial in character:

I

General Observations

- Lyme Disease and other tick-borne related illnesses are affecting significant and growing numbers of Virginians
- These diseases are present in every region of Virginia
- Virginia is in a particularly vulnerable geographical location, being at the crossroads of the frontline of expansion of Lyme disease carrying ticks from the North and other tick populations that have entered Virginia from the South, the public health risks of which are uncertain. These diseases can have significant, life-altering impact on patients, especially when the diagnosis is not made shortly after the patient is infected.
- Lyme disease is caused by a spirochete bacterium in the same family as syphilis. It can invade multiple organ systems and has a variable multi-stage progression with a tremendous range of symptoms. It is thought that humans develop no long-term immunity and there is no available vaccine.
- There is much that remains to be understood about Lyme and related diseases in every relevant sector including diagnosis, treatment, and prevention.
- There is an acute need for greater research in all relevant spheres.
- Medical personnel need accurate, fact-based information about prevalence, diagnosis, treatment, and prevention of tick-borne diseases. It is critical to raise awareness in the medical community about Lyme and other tick-borne diseases.
- The mandatory reporting of Lyme disease to the Virginia Department of Health (VDH) can be overlooked or forgotten by some medical providers, leading to an undercount of the number of patients affected.

- The CDC case definition for Lyme disease is for epidemiological purposes only and is not now and never has been the singular valid basis for a diagnosis of Lyme disease.
- Public awareness concerning the prevalence, symptoms and prevention of Lyme disease needs significant expansion.
- Significant improvements that can help to prevent Lyme disease are possible. This will require a concerted, multifaceted effort requiring the cooperation and action of every sector of Virginia—governmental, private, business, community, family, and individual.

II

General recommendation

Recommendation:

The task force should recommend that VDH receive funding to enhance its tick-borne diseases program. Key elements of an effective program include the following:

(i) human disease surveillance

(ii) tick surveillance and testing

(iii) general public and healthcare provider outreach and education regarding the prevalence and prevention of Lyme disease.

Any reference to education in these recommendations should emphasize the need to provide an open and balanced review of the full body of literature.

Rationale:

Lyme disease is a significant health issue in Virginia, and VDH has been working to track and prevent spread of this infection over the last decade. As Lyme disease has become increasingly problematic in Virginia during the last five years, surveillance and prevention activities have become increasingly labor and resource intensive. A strategic public health investment is necessary to enhance VDH's ability to prevent and control the spread of tick-borne diseases.

III

Specific Findings and Recommendations

In addition to these general observations, we make the following specific findings and recommendations based on the testimony that we received from our hearings:

A.

Diagnosis

1. As acknowledged by the CDC, Lyme disease and many related tick-borne illnesses cannot be adequately diagnosed by serology alone in many cases.
2. There is no serological test that can "rule out" Lyme disease.
3. Clinical diagnosis that *may* be supported by serology remains the proper method for the diagnosis of Lyme and related illnesses.
4. Clinical diagnosis is not limited to the observation of an EM rash. A significant proportion of patients with Lyme disease may never develop or observe such a rash. Moreover, the EM rash can manifest in non-traditional patterns. The medical community needs a more comprehensive set of visual illustrations so that non-traditional patterns may be properly recognized.
5. Many lay witnesses testified that members of Virginia's medical community inaccurately believed that serology alone can "rule out" Lyme disease.
6. According to lay testimony, there are some members of the Virginia medical community who have refused to consider a diagnosis of Lyme and related illnesses on the ground that "we do not have Lyme in Virginia" or in this "part of Virginia." Lyme disease is present in all parts of Virginia, endemic in

most parts of the state, and emerging throughout the Commonwealth.

7. The testimony that came before the Task Force relayed the highly questionable nature of the ELISA test for early localized disease. We encourage the use of clinical judgment at all stages due to the significant limitations of current serology.
8. We recommend that the VDH reporting form include the disclaimer "The CDC case definition is designed for surveillance purposes only. Clinical judgment should be exercised in assessing patients for Lyme disease as meeting the surveillance case definition is not required for the diagnosis of Lyme disease."
9. Since ticks often carry multiple pathogens and we received testimony that many Virginians have multiple tick-borne illnesses that may require comprehensive analysis and treatment, the medical community should be educated on the presence of co-infections.
10. Great caution should be taken whenever a blacklegged tick is attached and especially if it is engorged. Patient reports about the length of time of attachment can be unreliable as some patients may not have observed the exact moment of attachment. Medical providers should be at their liberty to treat Lyme disease prophylactically in such cases because of the high risk of disease. (Note that single-dose prophylaxis may lower the sensitivity of subsequent serology, as stated by the CDC.) Moreover, it is clear that early treatment is very important to prevent many serious complications of Lyme disease.
11. The Task Force encourages increased financial support for Internal Review Board-approved, peer-reviewed clinical studies associated with Lyme disease diagnosis and treatment. The Task Force encourages financial support for Virginia's college and university researchers who undertake research on Lyme or tick-borne disease. This should include

all scientific realms. We commend Old Dominion University for undertaking vital research in the Tidewater region. (Rationale: Additional research that investigates the validity and reliability of diagnostic and preventative tools and provides guidance for appropriate treatment will support quality of care and patient outcomes.)

12. The Task Force encourages institutions offering graduate-level medical degrees to offer comprehensive instruction about Lyme and other tick-borne diseases. Due to the rapidly evolving nature of the scientific research and literature on tick-borne disease, medical educators should use due diligence to teach comprehensive and up-to-date information in all aspects of tick-borne disease. (Rationale: Student clinicians (medical, nurse practitioner and physician's assistant students) are the clinicians of the future and should be aware of Lyme and other tick-borne diseases as medical conditions in Virginia.)
13. VDH should continue to provide information to clinicians practicing in the Commonwealth concerning the epidemiology of Lyme disease in Virginia, a physician's responsibility to report Lyme disease, the information VDH requires to classify a case, the purpose of the surveillance case definition, Lyme disease prevention measures and tick identification. VDH should also continue to provide information to clinicians practicing in the Commonwealth about other tick-borne diseases in Virginia. (Rationale: This recommendation articulates VDH's current practice and speaks to its commitment to continue these informational efforts in regard to tick-borne disease, with a particular focus on Lyme disease as it is the most commonly reported tick-borne disease and is present in all parts of Virginia, endemic in most parts of the state and emerging throughout the Commonwealth.) VDH should emphasize that due to the rapidly evolving nature of the scientific research and literature on Lyme and tick-borne

disease, medical professionals should use due diligence to stay abreast of information in all aspects of tick-borne disease to educate their ability to clinically assess patients.

B.

Treatment

1. There is no serological test that can tell a medical provider when a patient has been cured of Lyme disease.
2. A typical criterion that a patient is well is when the symptoms have resolved and the patient feels better.
3. There is no scientific basis for concluding that 30 days or less of antibiotics is sufficient treatment for every case of Lyme disease.
4. We received substantial testimony from lay witnesses that they had been successfully treated with long-term antibiotics.
5. Expert testimony regarding effectiveness of long-term antibiotics conflicted. We encourage additional studies to evaluate the effectiveness of long-term antibiotics as treatment for Lyme disease.
6. The Department of Health Professions should inform its licensees that the department does not target clinicians for disciplinary action by virtue of their antibiotic choice of management of Lyme disease.
7. Lay witnesses expressed displeasure with the propensity of the medical community to treat persons who were ultimately diagnosed as late stage Lyme disease as needing psychological evaluation or treatment. Lay witnesses testified this was often done in a demeaning fashion and appeared as an excuse for the medical community's failure to adequately understand the problem of Lyme disease.
8. Lay witnesses stated that long term treatment of Lyme disease is often not covered by their insurance carriers and that they can spend thousands of dollars per month for their treatment

plan. The extent to which this is occurring is unknown to the Task Force and the Task Force recommends that this issue be evaluated by the Bureau of Insurance.

C.

Public Education and Prevention

1. It is a public health goal of a high magnitude to ensure that the general public and medical community become fully aware of the risk of exposure to Lyme and related illnesses and the severe medical consequences that can arise when this disease is not promptly diagnosed and treated. Developing an appropriate sense of public urgency is the greatest single need in the efforts to prevent and treat Lyme disease. The Governor and VDH should expand their current programs of public education to place significant and regular emphasis on Lyme disease so that the public understanding is proportional to the serious nature of this threat to public health.
2. Since ticks often carry multiple pathogens and we received testimony that many Virginians have multiple tick-borne illnesses that may require comprehensive analysis and treatment, the public should be educated on the presence of co-infections.
3. The VDH and other appropriate state and local agencies should place greater emphasis on public education through modern media. In addition to printed brochures, public interest radio and television ads should be developed. The use of the internet should be dramatically amplified. Major internet information organizations—especially those headquartered in Virginia—should be asked to consider donating space for articles and announcements. An increased effort to work with the journalists of Virginia to develop appropriate stories to alert the public should be considered.

For example, Old Dominion University scientists presented their unanticipated discovery of two additional tick species in Tidewater some of which carried an infection that is a cousin of Rocky Mountain Spotted Fever. This example demonstrates the imperative for better communications on all fronts. Budgets appropriate for these purposes should be developed.

4. It is essential that the Virginia approach to Lyme disease prevention and treatment involve collaborative work of all branches of state government and coordination with all facets of local government. The Governor should consider convening a task force of state and local officials to create a best-practices model for government within the Commonwealth. For example, it is imperative that public schools and departments of parks and recreation consult with public health officials to properly manage facilities to prevent unnecessary public exposure to ticks—especially for children—and that warning signs be posted at points of public access in areas that are high-risk.
5. As a part of the efforts to inform the public about safe practices (e.g. how to keep your yard free from ticks), the Commonwealth should clearly communicate the expectation that government agencies actually implement the same methods being recommended to the public. For example, if a public school sends a tick prevention brochure home with a student, but does not actually implement the recommended practices on school property, there are two dangers that arise. First, children are unnecessarily exposed to ticks while at school. Second, the failure of the school to implement the practices signals to the parents that the situation is not truly important. Government must practice what it preaches if the public is going to give Lyme disease prevention the serious attention it deserves.
6. The General Assembly may wish to consider amending the *Code of Virginia* in order to authorize localities to establish tick

surveillance and control districts. (Rationale: Localities are already authorized by the *Code* to establish mosquito control districts. Providing a mechanism whereby localities could form tick surveillance and control districts could be beneficial to many localities, particularly in Lyme endemic and emerging areas, by allowing the development of practices and policies designed to decrease tick populations on locality property frequented by the general public such as public parks and schools.)

7. The Governor should establish a working group, under the auspices of the Secretary for Natural Resources in collaboration with the Secretary of Health and Human Resources, to develop guidance and potential strategies for localities that wish to attempt deer and/or tick population control. The Governor should include funding in the 2012 Budget Bill that is sufficient to adequately support this initiative. (Rationale: Developing guidance in this manner will allow for the development of control strategies that are more comprehensive than either Secretariat currently offers in regard to Lyme and other tick-borne diseases.)
8. Public education programs on Lyme prevention should continue to emphasize these (and other) important practices:

<u>Land-use practices for preventing tick exposure</u>:

- Animal exclusion and landscaping

Homeowners should consider fencing and landscaping choices that tend to exclude deer (the primary adult tick host) and mice (the Lyme bacterium reservoir). Do not plant vegetation that attracts deer, remove food and cover that attracts mice (e.g. wood piles trash), and reduce tick breeding grounds (e.g. clear trees and brush and regularly mow grass). Homeowner associations and other real estate contracts should avoid clauses that restrict the ability of

homeowners to effectively exclude deer from their property or control deer populations in their neighborhoods.

- Tick control

Local, state, and federal agencies should continue to evaluate the utility of host-specific application of acaricides (e.g., USDA 4-poster devices) to combat Lyme disease in this Commonwealth. If their use is warranted, the Virginia Department of Game and Inland Fisheries (DGIF) should put in place an orderly and responsible permitting process. DGIF is working with localities to investigate if this tool is a practical solution for managing tick populations. Currently, DGIF is working with Fairfax County on such a study and will develop potential permit conditions that will safeguard wildlife populations and habitats while not inhibiting the use of the 4-poster system. Current regulations and codes exist to allow for the supervised use of these devices. DGIF should work with VDH and local governments to make sure that proper safeguards are put in place and necessary data is collected on the use of these devices. Budget for tick testing should be considered by the General Assembly.

- Deer Control

DGIF is to be commended for its appropriate expansion of hunting seasons and limits for deer. Further expansions should be considered. Public information campaigns should be conducted to encourage all willing Virginians to participate in an effort to achieve appropriate deer populations for the sake of public health.

- Acaricides

Public information about the safe and appropriate use of acaricides should be a component of public education efforts.

Human practices to limit exposure to ticks:

- Avoiding tick habitat

The public needs to be informed about the nature of tick habitat and the danger of entering into such habitat unprepared.

- Appropriate dress and/or repellants (especially in tick habitats)

When entering such habitat is necessary, the public needs to be informed about best practices to avoid tick exposure (proper dress, repellants, tick checks, etc.)

- Showering after being outdoors

The public needs to be informed of the value of a thorough shower within a short time after concluding outdoor activities where tick exposure has been possible.

- Evening tick check

The public should be informed of the necessity of a once-a-day thorough tick check after being outdoors (especially in tick habitat). Children especially should be checked daily.

- Proper pet practices

Vaccination and repellants for pets should be strongly encouraged. The public should be aware that even though pets have been properly treated, they can still bring ticks into the home that leave the pet and bite a human. Accordingly, indoor pets should be controlled to avoid entry into tick habitat.

D.

Children

1. One expert testified concerning a potential for in utero transmission of Lyme disease. The CDC has proclaimed on its website, "Untreated, Lyme disease can be dangerous to your unborn child."[1] VDH should include information for pregnant women in the educational materials that it provides to the general public and to healthcare providers who care for pregnant women.
2. VDH should inform the public of the fact that children are a high-risk group for contracting Lyme disease. Parents need to be alert to the possibility of Lyme—especially when a child presents with symptoms that are not easily categorized as some other illness with an identified etiology.
3. VDH needs to undertake focused campaigns to help educate pediatricians, family practitioners, urgent care clinicians, and other clinicians about the importance of early recognition of Lyme disease.
4. VDH, the Virginia Department of Education, other agencies, and subject matter experts as appropriate should collaborate to create a best practices document focused on children with Lyme and related illnesses. Topics that should be considered include:

    - Proper construction of school grounds to promote deer exclusion and avoid unnecessary exposure to ticks

    - Before taking students outdoors for instructional field investigations, consideration of the site's likelihood for ticks

---

[1] http://www.cdc.gov/lyme/resources/toolkit/factsheets/10_508_Lyme%20disease_PregnantWoman_FACTSheet.pdf

and then, in cooperation with parents, preparation of the students, parents, and teachers accordingly with the following simple guidelines: wear appropriate clothing, use repellents and perform thorough tick checks. (The benefits of outdoor recreation and education is very important for our children's development and complete avoidance of tick habitat would be extremely difficult.)

- Proper landscaping and fencing practices to limit the ability of children to enter tick habitat during the school day
- Consideration of safe and effective use of acaricides
- Education of teachers, school psychologists, school counselors, school nurses, and other professionals in all phases of Lyme disease, but especially in the relationship between Lyme and neurological impairment that may present as learning-related or sudden-onset attention or memory difficulties.

5. VDH should continue to provide information to school nurses in the Commonwealth about Lyme and other tick-borne diseases in Virginia. (Rationale: This recommendation articulates VDH's current practice and speaks to its commitment to continue these critical informational efforts.)
6. Experts testified that students afflicted with this disease often fall significantly behind in school because of the problems that they face, not the least of which are cognitive difficulties. Current educational accommodations are often inadequate. Consideration should be given to appropriate and sensitive educational modifications for students with late-stage Lyme that help maximize their educational progress and that emphasize the fact that late-stage Lyme disease routinely has waxing and waning symptoms not typical in most chronic medical conditions and that may require novel and timely accommodations and interventions.

7. VDH should continue collaboration with Virginia's Department of Education (DOE), the Virginia Council for Private Education and home schooling associations to explore developing materials that may be incorporated into the science and/or health education curricula of elementary, middle and high school students in the Commonwealth concerning the epidemiology of Lyme and other tick-borne diseases in Virginia, tick-borne disease prevention methods and tick identification. (Rationale: Educating children about Lyme and other tick-borne diseases is best done by presenting this information as part of a school program. A comprehensive approach to educating elementary, middle and high school students about Lyme and other tick-borne diseases can only be achieved through a coordinated effort with the organizations that develop these academic programs for students in Virginia.)

Respectfully submitted,

Michael Farris
Chairman