

TICK-BORNE DISEASE WORKING GROUP RECOMMENDATIONS

Before Recommendations Decided at Public Meeting #6 — *Versus* — After Recommendations to Vote on at Public Meeting #7

BOLD & YELLOW = PROPOSED CHANGES; excludes capitalization changes to standardize the presentation and formatting of all recommendations.

Chapter: Recommendation #	Voted On / Approved Old Language	Copyedited New Proposed Recommendation	7/24 VOTE
EPIDEMIOLOGY and ECOLOGY			
Epi Eco: Rec 2.1	TO FUND STUDIES AND ACTIVITIES ON TICK BIOLOGY AND TICK BORNE DISEASE ECOLOGY INCLUDING SYSTEMATIC TICK SURVEILLANCE EFFORTS PARTICULARLY IN REGIONS BEYOND THE NORTHEAST AND UPPER MIDWEST.	Fund studies and activities on tick biology and tick-borne disease ecology, including systematic tick surveillance efforts particularly in regions beyond the Northeast and upper Midwest.	YES
Epi Eco: Rec 2.2	Fund systematic studies and activities to identify and characterize novel tick-borne disease agents in the United States.	No change	NO
Epi Eco: Rec 2.3	Support economic studies and activities to estimate the total cost of illness associated with tick-borne diseases in the United States, beginning first with Lyme disease and including both financial and societal impacts.	No change	NO
Epi Eco: Rec 2.4	Have public health authorities formally recognize complimentary, validated systematic approaches to tick-borne disease surveillance for humans, such as systematic sampling of tick-borne disease reports for investigation that reduce the burden on tick-borne disease reporting but allow for comparability of surveillance findings across states and over time.	No change	NO
Epi Eco: Rec 2.5	The Lyme disease surveillance criteria are not to be used ALONE for diagnostic purposes; public health authorities shall annually and when opportune (such as during Tick-Borne Disease Awareness Month) communicate this and inform doctors, insurers, state and local health departments, the press, and the public through official communication channels including the CDC's Morbidity and Mortality Weekly Report (MMWR).	The Lyme disease surveillance criteria are not to be used alone for diagnostic purposes; public health authorities shall annually and when opportune (such as during Tick-Borne Disease Awareness Month) communicate this message to doctors, insurers, state and local health departments, the press, and the public through official communication channels, including the CDC's Morbidity and Mortality Weekly Report (MMWR).	YES

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PREVENTION			
Prevention: Rec 3.1	FUND ADDITIONAL STUDIES AND ACTIVITIES ON THE DEVELOPMENT AND EVALUATION OF NOVEL AND TRADITIONAL TICK CONTROL METHODS THAT HAVE SHOWN PROMISE IN OTHER AREAS OF PUBLIC HEALTH ENTOMOLOGY.	Fund additional studies and activities on the development and evaluation of novel and traditional tick control methods that have shown promise in other areas of public health entomology.	YES
Prevention: Rec 3.2	BUILD TRUST – TRANSPARENT MECHANISM BY WHICH ALL STAKEHOLDERS EXAMINE AND DISCUSS PAST VACCINE ACTIVITIES AND POTENTIAL ADVERSE EVENTS TO INFORM FUTURE VACCINE DEVELOPMENT IN LYME DISEASE.	Build trust via a transparent mechanism by which all stakeholders examine and discuss past vaccine activities and potential adverse events to inform future vaccine development in Lyme disease.	YES
Prevention: Rec 3.3	SUPPORT SAFE AND EFFECTIVE Human Vaccines to Prevent Lyme Disease WITH TRANSPARENT MECHANISM BY WHICH ALL STAKEHOLDERS EXAMINE AND DISCUSS PAST VACCINE ACTIVITIES AND POTENTIAL ADVERSE EVENTS TO INFORM FUTURE VACCINE DEVELOPMENT IN LYME DISEASE.	Support the development of safe and effective human vaccines to prevent Lyme disease with transparent mechanisms by which all stakeholders examine and discuss past vaccine activities and potential adverse events to inform future vaccine development.	YES
Prevention: Rec 3.4	Education - Inform clinicians and general public of regional and specific risks related to tick illnesses.	Prioritize education by informing clinicians and the public about the regional and specific risks related to tick-borne disease.	YES

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DIAGNOSTICS			
Diagnostics: Rec 4.1	Need TO EVALUATE NEW TECHNOLOGY OR APPROACHES FOR THE DIAGNOSIS OF LYME DISEASE AND OTHER TICK-BORNE DISEASES.	Evaluate new technology or approaches for the diagnosis of Lyme disease and other tick-borne diseases.	NO
Diagnostics: Rec 4.2	NEED TO INCLUDE Special populations, ESPECIALLY CHILDREN, IN LYME DISEASE AND OTHER TICK-BORNE DISEASES DIAGNOSTIC STUDIES.	Include special populations, especially children, in Lyme disease and other tick-borne diseases diagnostic studies.	NO

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TREATMENT			
Treatment: Rec 5.1	Continued research into the pathogenesis (that is, immune response, cross-reactivity, autoimmunity, bacterial persistence, CO-INFECTIONS AND OTHER MECHANISMS) of persistent symptoms in patients who have received standard treatment regimens FOR TICK-BORNE DISEASES INCLUDING LYME DISEASE.	Prioritize research into the potential pathogenic mechanisms (such as, immune response, cross-reactivity, autoimmunity, bacterial persistence, co-infections, and other mechanisms) of persistent symptoms in patients who have received standard treatment regimens for tick-borne diseases, including Lyme disease.	YES
Treatment: Rec 5.2	Promote research on animal models of <i>B. burgdorferi</i> infection and the mechanisms of disease processes in humans with an emphasis on pathologies that are currently lacking, e.g., neuroborreliosis.	Promote research on animal models of <i>Borrelia burgdorferi</i> infection (that is, Lyme disease) and the mechanisms of disease processes in humans with an emphasis on pathologies that are currently lacking, for example, neuroborreliosis.	YES
Treatment: Rec 5.3	(INCLUDING TRANSMISSION VIA THE BLOOD SUPPLY AND PREGNANCY), AND TREATMENT OF OTHER TICK-BORNE DISEASES AND CO-INFECTIONS.	Improve the education and research on transmission (including transmission via the blood supply and pregnancy) and treatment of other tick-borne diseases and co-infections.	YES
Treatment: Rec 5.4	CONDUCT ADDITIONAL CLINICAL TRIALS APPROPRIATE TO THE TARGET POPULATIONS WHERE GAPS MAY EXIST.	No change (other than removing ALL CAPS)	NO
Treatment: Rec 5.5	IMPROVE THE EDUCATION AND RESEARCH ON THE PATHOGENESIS OF ALPHAGAL MEAT ALLERGY.	Improve the education and research on the pathogenesis of alpha-gal allergy, also known as the tick-caused “meat allergy.”	YES

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ACCESS TO CARE / PATIENT OUTCOMES			
Patient: Rec 6.1	CREATE A FEDERAL REPOSITORY FOR INFORMATION ON LYME DISEASE AND OTHER TICK-BORNE DISEASES TO ENCOMPASS:	Create a federal repository for information on Lyme disease and other tick-borne diseases.	YES
Patient: Rec 6.2	Allocate increased funding for tick-borne disease in the area of research, treatment, and prevention PROPORTIONAL TO BURDEN OF ILLNESS AND NEED.	Allocate increased funding for tick-borne disease in the areas of research, treatment, and prevention proportional to the burden of illness and need.	YES

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Patient: Rec 6.3	<p>Ensure the rights of those dealing with Lyme disease and TBDs by reducing the burden of the processes under which patients are currently diagnosed and treated and by which they access care. Basic protections must include, but not necessarily be limited to, those that:</p> <p>6.(3a) Protect patients from employment discrimination.</p> <p>6.(3b) Protect students of all ages from discrimination.</p> <p>6.(3c) Protect patients from healthcare and disability insurance coverage and reimbursement policies that are unduly burdensome.</p> <p>Major Issue/Controversy — Testing and Diagnostic Bands: How They Are Used Today and What That Is Doing to Patients</p> <p>(3d) Protect the rights of licensed and qualified clinicians to use individual clinical judgment, as well as recognized guidelines, to diagnose and treat patients in accordance with the needs and goals of each individual patient.</p>	<p>Ensure the rights of those dealing with Lyme disease and tick-borne diseases and conditions by reducing the burden of the processes under which patients are currently diagnosed and treated and by which they access care. Basic protections must include, but not necessarily be limited to, those that:</p> <p>6.(3a) Protect patients from employment discrimination.</p> <p>6.(3b) Protect students of all ages from discrimination.</p> <p>6.(3c) Protect patients from health care and disability insurance coverage and reimbursement policies that are unduly burdensome.</p> <p>(3d) Protect the rights of licensed and qualified clinicians to use individual clinical judgment, as well as recognized guidelines, to diagnose and treat patients in accordance with the needs and goals of each individual patient.</p> <p>Major Issue 6.4 — Testing and Diagnostic Bands: How They Are Used Today and What That Is Doing to Patients</p> <ul style="list-style-type: none"> • Empower patients with data • Engage diverse stakeholders • Relay information as a neutral knowledge broker 	YES

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LOOKING FORWARD			
	NIH: Create NIH TBD strategic plan, with public input during creation and implementation, to address tick-borne diseases including all stages of Lyme disease and coordinate research funding across NIAID, NINDS, NIAMS and NIMH to increase knowledge of pathogenesis, improve diagnosis and develop and test new therapeutics for tick borne diseases. Update every 5 years.	NIH: Create an NIH tick-borne disease strategic plan, with public input during creation and implementation, to address tick-borne diseases, including all stages of Lyme disease. Include in the plan the coordination of research funding across NIAID, NINDS, NIAMS, and NIMH to increase knowledge of pathogenesis, improve diagnosis, and develop and test new therapeutics for tick-borne diseases. Update every five years.	YES
	CDC: Dedicate funding within CDC with performance indicators to study babesiosis incidence, prevalence, treatment resistance, and prevention including maternal-fetal and transplantation/transfusion transmission risk. Consider using advanced data tools such as patient registries to study potential role of <i>Babesia</i> in tick borne disease patients with continuing manifestations of disease after initial treatment.	CDC: Dedicate funding within CDC— with performance indicators — to study babesiosis incidence, prevalence, treatment resistance, and prevention, including maternal-fetal and transplantation/transfusion transmission risk. Consider using advanced data tools, such as patient registries, to study the potential role of <i>Babesia</i> in tick-borne disease patients with continuing manifestations of disease after initial treatment.	NO
	DoD: Commence study of TBD incidence and prevalence of U.S. active duty and their dependents. Compile data on impact of TBD on military readiness. Create education and preparedness programs specifically geared to unique risks faced by military in training and deployment and their families.	DoD: Commence study of tick-borne disease incidence and prevalence of U.S. active duty and their dependents. Compile data on the impact of tick-borne diseases on military readiness. Create education and preparedness programs that specifically address the unique risks faced by military in training and on deployment, and by their families.	YES
	VA: Commence study of TBD incidence and prevalence of veterans and eligible family members.	VA: Commence study of tick-borne disease incidence and prevalence of V eterans and eligible family members.	YES

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