Name of Subcommittee: Disease Vectors, Surveillance, & Prevention Report to Tick-Borne Disease Working Group

Presenters: Patricia (Pat) Smith, Lyme Disease Association, Inc C. Ben Beard, CDC – Division of Vector-Borne Diseases

Tick-Borne Disease Working Group Meeting #4 May 10, 2018

### Disclaimer



Information and opinions are those of the presenter(s) and do not necessarily reflect the opinions of Working Group members or the Department of Health and Human Services.

# Background: Charge to the group



- The incidence and distribution of Lyme disease and other reportable tick-borne illnesses are increasing across the United States.
- In the absence of a vaccine in the U.S. against any of the tick-borne diseases, effective primary prevention relies on reducing exposure to ticks.
- Identifying and validating effective prevention and control strategies is critical for reducing the incidence of new cases.
- To track the effectiveness of national prevention and control strategies, it is essential to maintain an accurate understanding of current disease burden and trends against which to measure success of national prevention goals once established.
- The Disease Vector, Surveillance, and Prevention Subcommittee was established with the charge to look closely into the current status, needs, and challenges in understanding the biology and ecology of tick vectors, conducting human disease surveillance, and preventing disease.

### Background: Challenges related to disease vectors

- In recent decades, the distribution of the important tick vectors of human and animal illnesses have increased steadily and significantly.
- The number of counties in the U.S. where *Ixodes scapularis*, the vector for Lyme disease, anaplasmosis, babesiosis, and Powassan virus disease, is now established has doubled in the last 20 years the reasons are complex and vary by region.
- Due to the lack of a coordinated national tick vector surveillance program, there are significant gaps in information on local distribution of tick vectors, which is badly needed for educating the public health community, healthcare providers and the general public about local disease risk.
- There is a need to better understand the pathogens and vectors associated with tick-borne diseases, particularly in the southern and western U.S., and additional concerns about the risk of introduction of exotic tick species and pathogens.

### Background: Challenges related to surveillance

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- Lyme disease is the most common vector-borne disease reported and the sixth most common of all nationally notifiable diseases.
- While approximately 35,000 cases of Lyme disease are reported each year to the CDC, the actual number of annual cases exceeds 300,000.
- Under-reporting is common among high-incident diseases, and Lyme disease underreporting is further complicated by a case definition that requires both laboratory and supportive clinical data for confirmation of later stage cases.
- National disease reporting, while coordinated by CDC, is formally a responsibility of state governments through the Council of State and Territorial Epidemiologists.
- Under-reporting and inconsistencies in surveillance data from state to state and from year to year significantly hamper efforts to raise public awareness of the magnitude of the problem and provide data needed to evaluate prevention effectiveness.



- Primary prevention of tick-borne diseases relies on methods focused on reducing exposure of people to infected ticks.
- While there are a number of tools and methods available for killing and repelling ticks, the data available to show that any of these tools when deployed as directed actually prevents human illness is very limited.
- New methods and products are badly needed as well as controlled field trials that measure epidemiologic outcomes in order to provide data-driven prevention recommendations.
- The internet is all too often an easily available source of misinformation, directing those at risk to prevention methods that are ineffective and potentially even harmful.



- A key factor that crosscuts each of these major challenges is the critical lack of federal funding and other resources in comparison to other important areas of human health.
- The goals of the report from this subcommittee were to review the state of the science relating to the three primary areas tick vectors, human disease surveillance, and prevention, identifying critical gaps in information and specific resource needs.
- Based on this assessment, prioritized recommendations were drafted to assist in guiding national policy to address these needs.

### 13 total committee members

- 3 federal members
- 10 public members
  - 5 from academic institutions
  - 1 from industry
  - 4 patients or family members of patients (all also advocates)

Thank you to the subcommittee members!

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Range of experience:

- Tick biology and ecology
- Microbiology
- Human and tick surveillance
- Tick-borne disease prevention and control
- Public and healthcare provider education
- Advocacy
- Patient education and support
- Congressional affairs

### Subcommittee members – 3



Name	Туре	Role
Patricia (Pat) Smith	Public	Member, Committee co-chair
C. Ben Beard MS, PhD	Federal	Member, Committee co-chair
Jill Auerbach	Public	Member
Neeta Connally, PhD, MSPH	Public	Member, lead writer
Katherine Feldman, DVM, MPH	Public	Member, lead writer
Thomas Mather, PhD	Public	Member, lead writer
Phyllis Mervine, EdM	Public	
Robyn Nadolny, PhD	Federal	Member
Adalberto (Beto) Perez de Leon, DVM, MS, PhD	Federal	Member, co-lead writer
Danniel E. Sonenshine, Ph.D.	Public	Member, lead writer
Jean I. Tsao, PhD	Public	Member
Monica M. White	Public	Member
Stephen Wikel, PhD	Public	Member, lead writer

# What was done in the subcommittee – 1



### Meetings

- A total of 10 meetings were held by webinar or conference call between February 23 and April 26, 2018.
- Three formal presentations were made to the group:
  - Surveillance for Lyme disease in the United States Dr. Paul Mead (CDC)
  - Tickborne disease prevention in the northeastern United States: Current strategies and challenges Dr. Neeta Connally (Western Connecticut State University)
  - Lyme disease in California: Ecology and epidemiology Dr. Bob Lane (Emeritus professor, University of California Berkeley)
- These presentations were invited to provide general background and overview for the priorities addressed by the subcommittee.
- Subcommittee participants contributed to the scientific background for report content through independent literature reviews and through their individual knowledge as experts in the field.

# What was done in the subcommittee – 2



Development of the working group report

- Five issues or priorities total were identified to be addressed in different sections of the report.
- Co-chairs suggested and subcommittee approved five members to be lead writers for the corresponding sections.
- Subcommittee members volunteered to assist the lead writers in drafting their sections most members participated in drafting one or more sections of the report.
- Subgroups worked on their parts online & on independent calls within their groups.
- On weekly subcommittee calls, subgroups had a time slot to discuss/receive input from entire subcommittee.
- Draft sections were then sent to the assigned HHS writer who collated the five sections into one report, standardized the format, compiled references, and organized tables and figures.
- The collated draft report was distributed to the entire subcommittee for discussion and comment.
- Votes were taken to approve the entire report, each individual section, and each recommendation made in each section.
- There was a high level of agreement on all but one section of the report (human disease surveillance and reporting, p3).
- Two minority reports were submitted.
- The overall subcommittee report was approved unanimously, with 2 minority reports (12-0-1A).
  - Each of the five sections was approved unanimously p1(10-0-3A); p2(10-0-3A); p3(11-0-2A); p4(12-0-1A); p5(12-0-1A).
  - Minority report addressing surveillance report language p3(4-7-2A).
- All but one of the prioritized actions to consider were approved unanimously, none were disproved (12-0-1A.).
  - One prioritized action to consider from vector programs section was approved by majority p5 (7-3-2 abstain-1A.).
  - Minority report prioritized action to consider approved (3-0).



### General comment

All subcommittee members actively participated in the development of this report. Members voted to approve submission of the report to the Working Group and on the wording of each of the possible actions contained in the report. The vote to submit the report indicates general agreement with content of the document, but it does not necessarily indicate complete agreement with each and every statement in the report.

# Primary themesTick vectors

- Human surveillance
- Prevention

# Key questions – Primary theme: tick vectors



What is our current knowledge of the following topics and what can be done to increase it?

- The need for better vector surveillance
- Geographic distribution and host feeding behavior of tick species involved in pathogen transmission cycles
- Novel and emerging pathogens including *Bartonella* in ticks (rapid molecular detection)
- Drivers of vector range expansion and vector and disease ecology
- A better understanding of vector competence and vectorial capacity

### Key questions – Primary theme: human surveillance



- How do CDC and CSTE work together in conducting national disease surveillance?
- How do surveillance policy changes get enacted?
- How can surveillance practices be improved and standardized from state-tostate and from year-to-year?
- Are there additional tick-borne diseases that should be nationallynotifiable?
- What is the role of other data sources and patient registries in defining national disease trends?
- Would CSTE consider other surveillance data other than case numbers?

# Key questions – Primary theme: prevention

- What tools are currently in our toolbox for tick population control and disease prevention and how extensively have they been evaluated?
- How can prevention education be improved, including providing accurate information and removing both personal and public obstacles?
- What are the most promising novel prevention tools that are on the horizon (eg. transgenic ticks and other novel molecular interventions such as RNAi)?
- How do we encourage commercialization of effective prevention tools and products?

# Potential actions: Key issues identified

Prioritized Key Issues:

- 1. The need for a better understanding of the geographic distribution of tick vectors, disease ecology and vectorial capacity, how these are changing over time, and the key entomological determinants of risks to humans, including tick behavior and vector competence.
- 2. The need for novel safe and effective tick or host-targeted interventions that have been adequately validated to reduce human disease incidence.
- 3. The need for improvements in national disease surveillance and reporting, and the potential role of other data sources and patient registries in defining national disease burdens and trends.
- 4. Detection, identification, and characterization of novel and emerging pathogens in ticks, including *Bartonella*, and the transmission risks of these agents by ticks to humans.
- 5. The need for better prevention education for patients and physicians, including providing accurate information and removing both personal and public obstacles.



Key Issue: The need for a better understanding of the geographic distribution of tick vectors, disease ecology and vectorial capacity, how these are changing over time, and the key entomological determinants of risks to humans, including tick behavior and vector competence.

- 1. Tick environment-habitat-host research. Fund field studies to identify key factors that contribute to tick presence and abundance, and how they can be interrupted (for example, climate, landscape change, or control of host populations). Particular emphasis should be placed on funding vector surveillance studies that can be compared among sites and over time to improve our understanding of tick species distribution and abundance. Fund research on enzootic cycles that sustain tick-borne pathogens in the natural environment, tick range expansions, and how they can be interrupted. Also identify and investigate Lyme disease vectors and hosts outside of the major Midwest and Northeast Lyme disease foci, to inform the medical community about the true distribution of the Lyme disease pathogen and other tick-borne pathogens, especially in California and the Southeastern United States.
- 2. Tick abatement programs. Fund stand-alone tick control programs OR incorporate tick control programs into existing local and regional mosquito control organizations (renamed as Vector Control Programs). Also achieve tick abatement by establishing public/private/university partnerships to translate promising new tick-control inventions into consumer products. Also, enhance the Small Business Innovative Research (SBIR) program for government investment in successful companies by adding a government purchasing phase to incentivize marketing and profitability.



Key Issue: The need for a better understanding of the geographic distribution of tick vectors, disease ecology and vectorial capacity, how these are changing over time, and the key entomological determinants of risks to humans, including tick behavior and vector competence.

- 3. Disrupt tick-borne disease infection and transmission. Fund research on modern molecular and genetic techniques (for example, gene knockdown, CRISPER/Cas9) to disrupt infection in the tick vector and transmission of tick-borne pathogens to humans and animals. Develop and disseminate vaccines against ticks to prevent the spread of these tick-borne disease agents.
- 4. Tick basic research. Fund research on pathogen-binding receptors and regulatory factors that enable tick-borne pathogens to infect the tick tissues, proliferate, and survive for transmission to humans and animals.
- 5. Genetically modified tick population. Fund research to create a genetically modified tick population, especially for the Lyme disease ticks, *Ixodes scapularis* and *Ixodes pacificus*, for release into highly endemic regions. Fund research to study the human dimensions of acceptance/barriers of acceptance of releasing GMO ticks.

### Potential actions – Key issue 2



Key issue: The need for novel safe and effective tick or host-targeted interventions that have been adequately validated to reduce human disease incidence.

- 1. Further study of proven tick-control measures (as evidence by lab and field studies) at the scale of population-based prospective studies to validate these measures for preventing human diseases
- 2. Field-trials and human studies evaluating effective natural tick-control products and natural skin repellents for tick control, tick bite, and human disease prevention (for example, use of skin lotions, soaps and repellents or tick control products containing nootkatone or other botanically-based ingredients)
- 3. Assessment of integrated tick management tools that have the greatest effectiveness for vector control while minimizing negative environmental impacts (such as groundwater pollution and non-target effects) and pesticide resistance
- 4. Continued study and development of promising novel tick- and pathogen-control measures, including molecular technologies, for impacting pathogen prevalence in ticks and animal reservoir hosts (for example, rodent vaccination, transgenic ticks, RNAi, semiochemical control, and so forth), and promotion of private and public partnerships to engage industry and other professionals to develop novel and effective products that can be marketed to the public for tick-borne disease prevention
- 5. Assessment of barriers to public adoption of prevention practices (for example, studies evaluating willingness-to-pay, social acceptability, environmental concerns, behavioral preferences, and knowledge, attitudes, and perceptions of prevention measures)



Key issue: The need for improvements in national disease surveillance and reporting, and the potential role of other data sources and patient registries in defining national disease burdens and trends.

- 1. Provide a more complete picture of disease risk by supplementing and integrating traditional public health surveillance data with other data sources such as tick surveillance data; tick testing data; companion animal tick-borne disease testing data; medical claims data; weather data; other patient data sources; and data from other federal agencies including the Department of Defense.
- 2. Have public health authorities formally recognize (for example, include on official websites and in official publications such as CDC annual reports) and provide resources for systematically determined, and regularly conducted, studies to determine estimates of the actual number of cases of tick-borne disease ("burden of illness" studies). Base allocations on the estimated actual number of cases of disease in addition to reported case counts.



Key issue: The need for improvements in national disease surveillance and reporting, and the potential role of other data sources and patient registries in defining national disease burdens and trends.

- 3. Have public health authorities formally recognize alternative, validated systematic approaches to tick-borne disease surveillance, such as systematic sampling of tick-borne disease reports for investigation, that reduce the burden on tick-borne disease reporters but allow for comparability of surveillance findings across states and over time.
- 4. Make it easier and more likely for tick-borne disease cases to get reported to public health agencies by leveraging electronic exchange of health data and educating and incentivizing providers to report.
- 5. Public health authorities shall annually and when opportune (such as during Tick-Borne Disease Awareness Month) inform doctors, insurers, state and local health departments, the press and the public through official communication channels, including the MMWR, CDC and other official websites, that the Lyme disease surveillance criteria are not to be used for diagnostic purposes.



Key issue: The need for improvements in national disease surveillance and reporting, and the potential role of other data sources and patient registries in defining national disease burdens and trends.

**Minority Response (4-7-2A) subcommittee members):** There was a unanimous vote to accept the proposed actions for this key issue, and although much is discussed and agreed to in the body of the report, there remained significant concern about the CSTE/CDC Lyme surveillance case definition and its misuse in clinical diagnosis. Based on the minority members' input over decades from patients and Lyme treating physicians, the report states that misuse of the overly narrow surveillance case definition led to widespread failure by physicians to diagnose and treat Lyme disease in patients who did not meet the surveillance criteria and by laboratories who would only report out CDC-recommended bands. The report's focus is that the government has not been responsive to the situation and did little to nothing to rectify the situation and exclusively promoted a set of guidelines which had been developed to use those surveillance criteria.

### Potential actions – Key issue 4



Key issue: Detection, identification, and characterization of novel and emerging pathogens in ticks, including *Bartonella*, and the transmission risks of these agents by ticks to humans.

Note: The group voted to select one potential action from all options in each of the five bullets it drafted for Working Group consideration. However, the group felt that all the five possible actions selected were equally important. The consensus was to take a theme approach to synthesize the five possible actions selected, and it presents a theme encompassing the potential action for the Working Group to consider. The theme and the 5 actions are presented below.

#### Potential action:

Theme: Encourage commitment to establish a nationwide tick and tick-borne disease surveillance network that is a partnership among public interest groups, academic institutions, and local, state and federal government agencies to provide coordinated, standardized protocols for tick-borne disease surveillance, tick collection, identification, and analysis to identify established, emerging, and enzootic transmission cycles with zoonotic potential. Proposed network includes the coordination of local Mosquito and Tick Control Programs.

- Rather than create a standalone tick and tick-borne disease network, the logical approach is to combine all medically important vectors, primarily mosquitoes and ticks, within one comprehensive operational scheme. Such an integrated surveillance and response system is reported to be effective and result in significant cost savings over specific vector and related disease approaches (Wu et al., 2016); 3) establish state and federal partnership to safeguard public health that is also linked to the National Animal Health Laboratory Network (https://www.aphis.usda.gov/aphis/ourfocus/animalhealth/lab-info-services/nahln/ct\_national\_animal\_health\_laboratory\_network).
- Establish interdisciplinary technical committee between the American Medical Association, the Veterinary Medical Association, and the Entomological Society of America (<u>http://www.entsoc.org/PDF/2015/ESA-PolicyStatement-TickBorneDiseases.pdf</u>) to produce guidance based on state of the science to study and validate tick-borne pathogens and tick vectors.

### Potential actions – Key issue 4



- 3. Establish global tick microbiome consortium similar to the Global Virome Project (http://www.globalviromeproject.org); 2) tick species to be included in tiered approach for further characterization of their microbiomes include the following ixodid vectors of zoonoses in the United States (Eisen, Kugeler, et al., 2017): *Amblyomma americanum, Amblyomma maculatum, Dermacentor andersoni, Dermacentor occidentalis, Dermacentor variabilis, Ixodes pacificus, Ixodes scapularis,* and *Rhipicephalus sanguineus, Ornithodoros* spp., which will enable the systematic identification of microbes potentially pathogenic to humans and animals through further research and testing as described in theme 2 above.
- 4. Establish a state and federal tick-borne disease council to develop best practices for maximal dissemination of science-based information, including interactive sites for tick identification in real time.
- 5. Study each of the major zoonotic tick-borne diseases in different ecosystems using harmonized protocols to understand the variability in qualitative and quantitative characteristics of ecological drivers.



Key issue: The need for better prevention education for patients and physicians, including providing accurate information and removing both personal and public obstacles.

- Focus future tick prevention education on those practices and activities with positively measured outcomes such as reductions in the number of ticks found on study participants or outcomes related to the tick encounters (bites, disease) a documented increase in knowledge, or the adoption of specific prevention behaviors; encourage a pipeline of innovation to science-based prevention education by providing additional funding for practitioners (both individuals and entities) proposing to conduct objective assessments of their intervention or tool.
- 2. Recommend significant additional funding for CDC-supported regional Centers of Excellence in Vector-borne Disease (CoEs) to expand their training, internship, and cross-discipline collaboration opportunities in high priority tick prevention education programs, including: servicing national crowd-sourced tick surveillance programs, conducting health promotion and social marketing studies, conducting applied studies to validate or dispel commonly promoted tools and strategies for tick prevention, and science communications training.
- 3. Incentivize innovation in best K-12 learning practices as well as evaluate the effectiveness of available and new learning kit resources.



Key issue: The need for better prevention education for patients and physicians, including providing accurate information and removing both personal and public obstacles.

- 4. Invest in programs that already effectively link the best of tick science to peoples' lived experiences with ticks (that is, Cooperative Extension, academic-based tick prevention resources, advocacy groups), and update existing regionally- and occupationally-relevant targeted public health intervention programs (including federal agency safety manuals and handbooks) to reduce physical and behavioral tick exposure risk by addressing specific gaps in knowledge and prevention.
- 5. Develop best practice tick control training materials (on-line training, videos) for PCOs, and make continuing education (CE) compliance a requirement for continuing PCO licensure.



Key issue: The need for better prevention education for patients and physicians, including providing accurate information and removing both personal and public obstacles.

**Minority Response (3-7-2abstain-1A) subcommittee members)** While there was a unanimous vote to accept the proposed actions for this key issue, the minority response addresses the need to remove the word "already" which limits the potential action to programs already in place for decades but which are primarily focused in regions with prevalence of blacklegged ticks and high incidence of Lyme. Large areas of the country are characterized as being low tick or low tick-borne disease incidence and thus lack awareness and resources for prevention measures relevant to their home states. New innovative or regionally relevant programs that can link the current best science to peoples' actual experiences with ticks is essential to improving prevention education in these underserved areas.

### Discussion



### **Challenges and Limitations**

- Lack of adequate time to research, draft, review, discuss and revise important content prior to voting on the final version for submission.
- Lack of time to have discussions with other subcommittees to address overlaps.
- Instructions were sometimes unclear and sometimes appeared slightly different in different documents, which then required extra time to get clarity and convey correct instructions to subcommittee.
- Limitations on the numbers of issues, questions, and priorities that could be included in this report

### Discussion



### **Big Picture**

- Due to the lack of a coordinated national tick vector surveillance program, there are significant gaps in information on local distribution of tick vectors, which is badly needed for educating the public health community, healthcare providers and the general public about local disease risk.
- There is a need to better understand the pathogens and vectors associated with tick-borne diseases, particularly in the southern and western U.S., and additional concerns about the risk of introduction of exotic tick species and pathogens.
- Under-reporting and inconsistencies in surveillance data from state to state and from year to year significantly hamper efforts to raise public awareness of the magnitude of the problem and provide data needed to evaluate prevention effectiveness
- New methods and products are badly needed for killing and repelling ticks as well as controlled field trials that measure epidemiologic outcomes in order to provide data-driven prevention recommendations.
- Current federal funding to support surveillance and prevention activities, as well as basic and applied research on tick biology, ecology and control is severely inadequate to address one of the largest public health problems in the U.S.