

HHS Tick-Borne Disease Working Group Member Resigns

Working Group Member Resigns (posted March 8, 2018) A member of the Tick-Borne Disease Working Group, Karen Vanderhoof-Forschner, resigned on March 6, 2018. Ms. Vanderhoof-Forschner also served as one of two co-chairs on the Access to Care Services and Support to Patients Subcommittee. Three non-federal subcommittee members were nominated by the other members to take on this leadership role. Early next week, subcommittee members will vote on their preference to replace Ms. Vanderhoof-Forschner.

Posted March 8, 2018 on U.S. Department of Health and Human Services (HHS) website

A member of the Tick-Borne Disease Working Group, Karen Vanderhoof-Forschner, resigned on March 6, 2018. Ms. Vanderhoof-Forschner also served as one of two co-chairs on the Access to Care Services and Support to Patients Subcommittee. Three non-federal subcommittee members were nominated by the other members to take on this leadership role. Early next week, subcommittee members will vote on their preference to replace Ms. Vanderhoof-Forschner. The results of the vote will be considered along with other information by the Chair and the Vice-Chair of the Working Group. A replacement for Ms. Vanderhoof-Forschner to serve on the Working Group will be appointed by Secretary Azar.

Click here for Working Group Updates on HHS website

Working Group Subcommittee Membership Update

The Department of Health and Human Services announces changes to the composition of three of the six subcommittees of the Tick-Borne Disease Working Group (Working Group). The changes were made in response to three members who did not accept the invitations they received to be a part of a subcommittee. New members were selected from the list of existing nominees by the Co-Chairs of the affected subcommittees. The Chair and Vice-Chair of the Working Group provided input and approved the final changes.

Update on Subcommittee Membership (posted March 2, 2018) from HHS website

The Department of Health and Human Services announces changes to the composition of three of the six subcommittees of the Tick-Borne Disease Working Group (Working Group). The changes were made in response to three members who did not accept the invitations they received to be a part of a subcommittee. New members were selected from the list of existing nominees by the Co-Chairs of the affected subcommittees. The Chair and Vice-Chair of the Working Group provided input and approved the final changes.

Robert Bransfield, MD, a private practice physician and Associate Clinical Professor in the Department of Psychiatry at Rutgers-RWJ Medical School, has replaced **Susan Green, JD**, on the Access to Care and Support to Patients subcommittee. After careful consideration, Ms. Green withdrew her name.

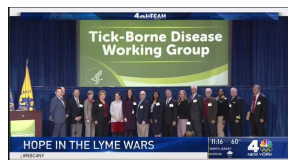
David Roth, JD, has accepted a Co-Chair position on the Testing and Diagnostics Subcommittee, of which he is an existing member. **Vanilla Singh, MD**, was not able to accept the invitation to serve as Co-Chair because of additional duties

she has been asked to perform in the Office of the Assistant Secretary for Health. Dr. Singh remains a federal member of the Tick-Borne Disease Working Group. **Holly Ahern**, MS, Associate Professor of Microbiology at SUNY Adirondack, has accepted a position on the Testing and Diagnostics Subcommittee.

David Walker, MD, who was selected for the Vaccine and Therapeutics subcommittee, withdrew his name for personal reasons. The subcommittee will proceed with the existing members

Click here for Working Group Updates on HHS website

Federal TBD Working Group Featured on NBC News NY



NBC News 4 New York aired a piece on the federal Tick-Borne Working Group, *Tri-State Helps Bring Hope to Lyme Wars Public Health Crisis*, on February 21, 2018. The video featured LDA President, Pat Smith; Lyme Society, Inc. President, Bob Sabatino; John Aucott, Co-Chair of the Working Group; as well as a number of patients.

Click here to watch the NBC clip

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The Tick-Borne Disease Working Group was established by the 21st Century Cures Act to improve federal coordination of efforts related to tick-borne diseases. Members will review all U.S. Department of Health and Human Services efforts related to tick-borne diseases to provide expertise and help ensure interagency coordination and minimize overlap, examine research priorities and identify unmet needs.

Click here to watch the NBC clip



Tri-State Helps Bring Hope to Lyme Wars Public Health Crisis

A major change is happening in the Lyme Wars with top experts taking action with help from people in the tri-state. Natalie Pasquarella reports.

Click here for Tick-Borne Disease Working Group News on LDA website

Click here for Working Group Updates on U.S. Department of Health and Human Services (HHS) website

53 Members Named to Serve on

Working Group Subcommittees



The Lyme Disease Association announces that the Department of Health and Human Services (HHS) has selected 53 individual to serve on one of six subcommittees of the Tick-Borne Disease Working Group (Working Group). After reviewing the nominations, selections were made by the co-chairs overseeing each of the subcommittees. The Chair and Vice-Chair of the Working Group provided input and approved the final selections. All of the individuals were notified today, but they have not yet confirmed their availability to serve on the subcommittee that they were chosen to join. The final list of subcommittee members will be updated if any of them are no longer able to join a subcommittee.

From the Department of Health and Human Services (HHS) webpage for the Tick-Borne Disease Working Group:



ting Deputy Dir., DVBD, CDC & Pat Smith, LDA President – Co-Chairs, HHS Working Group Disease Vectors, Surveillance, & Prevention Subcommittee

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After reviewing the nominations, selections were made by the co-chairs overseeing each of the subcommittees. The Chair and Vice-Chair of the Working Group provided input and approved the final selections. All of the individuals were notified today, but they have not yet confirmed their availability to serve on the subcommittee that they were chosen to join. The final list of subcommittee members will be updated if any of them are no longer able to join a subcommittee.

These subcommittees were established by the Working Group members during the December 12, 2017 meeting to assist them in identifying and reviewing information that provides the background, context, and evidence needed to develop the report to Congress and the HHS Secretary as required by the 21st Century Cures Act. The subcommittees will be led by members of the Working Group. The Chair and Vice-Chair of the Working Group will work in collaboration with the subcommittee Co-Chairs and the Designated Federal Officer to ensure that the work of the subcommittees is consistent with the needs of the Working Group and committee management laws and regulations. The roles of the subcommittees, the work they will be doing, and the reports that they will provide to the Working Group will be discussed at the February 12, 2018 meeting.

The members of the Tick-Borne Disease Working Group subcommittees are:

Disease Vectors, Surveillance, and Prevention Co-Chairs: Pat Smith and Ben Beard, MS, PhD	
Member	Affiliation
Jill Auerbach	Founder, Tick Research to Eliminate Diseases Founder, Stop Ticks On People (S.T.O.P.)

Neeta Connally, PhD, MSPH	Associate Professor, Tick-borne Disease Prevention Laboratory, Western Connecticut State
Katherine Feldman, DVM, MPH	Senior Epidemiologist, MITRE
Thomas N. Mather, PhD	Professor, Center for Vector- Borne Disease Director, TickEncounter Resource Center
Phyllis Mervine	President, LymeDisease.org
Colonel Robin Nadolny, PhD	COL, Medical Service Team Lead, Tick-Borne Disease Laboratory, Army Public Health Center
Adalberto Perez de Leon, DVM, PhD, MS	Director, Knippling-Bushland U.S. Livestock Insects Research Laboratory, United States Department of Agriculture- Agricultural Research Service
Daniel E. Sonenshine, PhD	Eminent Professor of Biological Science, Old Dominion University
Jean I. Tsao, PhD	Associate Professor, Departments of Fisheries and Wildlife and of Large Animal Clinical Sciences, Michigan State University
Monica M. White	President and Co-founder, Colorado Tick-Borne Disease Awareness Association LymeDisease.org, Lyme Disease Association, Inc., Public Tick IPM working group, Chaffee County Health Coalition

Stephen Wikel, PhD	Professor and Chair Emeritus of Medical Sciences, St. Vincent's Medical Center, Quinnipiac University
Pathogenesis, Transmission and Treatment Co-Chairs: Wendy Adams, MBA and Captain Estella Jones, DVM	
Member	Affiliation
Nicole Baumgarth, DVM, PhD	Professor, Center for Comparative Medicine and Dept. of Pathology, Microbiology & Immunology, UC Davis
Patricia K. Coyle, MD	Neurology Professor and Vice Chair, Dept. of Neurology Director, MS Comprehensive Care Center, Stony Brook University Medical Center
Sam Donta, MD	Fellow Infectious Diseases, Infectious Disease Society of America Consultant, Infectious Diseases
Brian Fallon, MD, MPH	Professor of Clinical Psychiatry, and Director, Lyme and Tick-Borne Diseases Research Center, Columbia University
Lorraine Johnson, JD, MBA	CEO, LymeDisease.org
Elizabeth Maloney, MD	President, Partnership for Tick-Borne Diseases Education
Jon Skare, PhD	Professor and Associate Head, Dept. of Microbial Pathogenesis and Immunology, Texas A & M University

Brian Stevenson, PhD	Professor, Department of Microbiology, Immunology & Molecular Genetics, University of Kentucky College of Medicine
Testing and Diagnostics	
Co-Chairs: Lise E. Nigrovic, MD, MPH and Co-chair to be determined	
Member	Affiliation
Charles Y. Chiu, MD, PhD	Director, Abbott Viral Diagnostics and Discovery Center, UCSF
Roberta DeBiasi, MD, MS	Chief, CNMC Division of Pediatric Infectious Diseases Director, Fetal Infectious Diseases Program Co-Director, Congenital Zika Program at Children's National
Noel Gerald, PhD	Biologist and Senior Scientific Reviewer, Office of In Vitro Diagnostics and Radiological Health, FDA
Deborah Hoadley, MD, MPH	Director, New England Institute for Lyme Disease and Tick-Borne Illnesses
Maliha Ilias, PhD	Program Officer, Lyme Disease Research Bacteriology and Mycology Branch, National Institute of Infectious Diseases, NIH
Bobbi Pritt, MD, MSc	Professor of Laboratory Medicine and Pathology, and Co-Director, Vector-Borne Diseases Laboratory Services, Mayo Clinic

David Roth, JD	Retired senior managing director of a private equity firm (Blackstone)
Steven Schutzer, MD	Professor of Medicine, Rutgers New Jersey Medical School
Access to Care Services and Support to Patients Co-Chairs: Karen Vanderhoof-Forschner, JD, MBA and Commander Scott Cooper, MMSc, PA-C	
Member	Affiliation
Ana Frost, PhD	The Institute for Functional Medicine
Holiday Goodreau	President and Executive Director, The LiveLyme Foundation
Susan Green, JD	Legislative Counsel, NatCapLyme
Enid Haller, LCSW, PhD	Executive Director, Lyme Center of Martha's Vineyard Martha's Vineyard Lyme Support Group
Paula Jones Jackson	President & Co-Founder, Midcoast Lyme Disease Support & Education (MLDSE)
Colonel Nicole Malachowski	Retired, US Air Force
Leonard Schuchman, DO, MPH, FAAFP	Osteopathic Physician
Sheila M. Statlender, PhD	Clinical Psychologist, Private Practice
Kathleen Steele, LCSW	Psychotherapist
Vaccine and Therapeutics Co-Chairs: Robert Smith, MD, MPH, FACP, FIDSA and Dennis Dixon, PhD	
Member	Affiliation

Felipe C. Cabello, MD	Professor of Microbiology and Immunology, New York Medical College
Monica E. Embers, PhD	Assistant Professor, and Director, TNPRC Vector-borne Diseases Core, Division of Bacteriology and Parasitology, Tulane National Primate Research Center
Maria Gomes-Solecki, PhD	Associate Professor, Department of Microbiology, Immunology and Biochemistry, University of Tennessee Health Science Center
Utpal Pal, PhD	Professor, University of Maryland
Stanley A. Plotkin, MD	Emeritus Professor of Pediatrics, University of Pennsylvania
Juan Salazar, MD, MPH, FAAP	Professor and Chair, Department of Pediatrics, University of Connecticut Medical School, and Physician in Chief and Executive VP, Connecticut Children's Medical Center
Leigh Ann Soltysiak, MS	Self-employed, Owner, Principal Commercialization & Strategy Consultant, Silverleaf Consulting, LLC

David H. Walker, MD	The Carmage and Martha Walls Distinguished University Chair in Tropical Diseases, and Professor, Department of Pathology, and Executive Director, Center for Biodefense and Emerging Infectious Diseases, The University of Texas Medical Branch
<p align="center">Other Tick-Borne Diseases and Co-Infections</p> <p align="center">Co-Chairs: Richard Horowitz, MD and Allen Richards, PhD</p>	
Member	Affiliation
Megan Dulaney, MS	Senior Interagency Liaison, DOD Center for Health Engagement, Uniformed Services University for the Health Sciences, Henry M. Jackson Foundation for the Advancement of Military Medicine
Marna Ericson, PhD	Assistant Professor, Department of Dermatology, and Director, Dermatology Imaging Center, University of Minnesota
Christine Green, MD	Physician, Green Oaks Medical Center, PC, and Director, LymeDisease.org
Charles Lubelczyk, MPH	Vector Ecologist, Maine Medical Center Research Institute
Ulrike G. Munderloh, DVM, PhD	Professor, University of Minnesota, Department of Entomology
Garth Nicolson, MD, PhD	President, Chief Scientific Officer and Emeritus Professor of Molecular Pathology, The Institute for Molecular Medicine

Christopher D. Paddock, MD, MPHTM	Rickettsial Zoonoses Branch, CDC
Samuel S. Perdue, PhD	Section Chief, Basic Sciences, Bacteriology and Mycology Branch, DMID/NIAID/NIH
Sam R. Telford III, ScD	Professor of Infectious Disease and Global Health Cummings School of Veterinary Medicine, Tufts University

Working Group Selects Sub-Committee Chairs/Cong. Smith Reports on Working Group



The Lyme Disease Association Inc. announces that the new HHS Tick-Borne Disease Working Group (TBDWG) has selected co-chairs from the TBDWG for its 6 newly formed sub-committees. LDA President Pat Smith will be co-chair the Disease Vectors, Surveillance and Prevention (includes epidemiology of tick-borne diseases) Subcommittee. The other co-chair is Dr. Ben Beard, Acting Deputy Director, Division of Vector-Borne Diseases. The co-chairs will work together to select members for their committee.



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Reports from the subcommittees will be presented to the TBDWG for that group's public deliberation. The Committees selected by the TBDWG and the newly designated chairs are as follows:

1. Disease Vectors, Surveillance and Prevention (includes epidemiology of tick-borne diseases). **(Pat Smith/Ben Beard)**
2. Pathogenesis, Transmission, and Treatment **(Wendy Adams/Estelle Jones)**
3. Testing & Diagnostics (includes lab-based diagnoses & clinical-diagnoses) **(Lise Nigrovic/Vanila Singh/Designee)**
4. Access to Care Services and Support to Patients **(Karen Vanderhoof Forschner/Scott Cooper)**
5. Vaccine and Therapeutics **(Dennis Dixon/ Robert Smith)**
6. Other Tick-Borne Diseases and Co-infections **(Richard Horowitz/Allen Richards)**

According to HHS, each subcommittee will be led by two subcommittee co-chairs. The co-chairs of each committee will work with the Working Group Chair, Vice Chair, the Designated Federal Official (DFO) and his alternate, and the other subcommittee co-chairs to align the work of the subcommittees with the goals and priorities of the Working Group and to conduct the work in a similar manner across subcommittees. It is expected that each subcommittee will have about 8-10

members, including two members who are members of the Working Group.

Congressman Christopher Smith Reports on HHS Working Group Creation & History

Congressman Chris Smith (NJ-4) has reported in his newsletter to his district on the working group formation and on the appointment of Pat Smith as a member of the working group. He includes a history of the process of getting legislation passed to create the TBDWG.

UPDATE: HHS has appointed a new member, Robert Smith, MD, MPH, for the Working Group to fill the vacancy left by Dr. Gary Wormser's withdrawal. New member Appointed to HHS Working Group

Related links

Congressman Chris Smith Newsletter Article on HHS Working Group

"A Golden Opportunity for Change on Chronic Lyme Disease" by Jerry Carino in Asbury Park Press

Videos of Meetings 1 and 2 of HHS Tick-Borne Disease Working Group

Transcripts, Agenda, and Videos of HHS Tick-Borne Disease Working Group Meetings 1 and 2

LDA President Appointed to HHS Tick-Borne Disease Working Group

HHS Working Group Sub Committee Chairs Currently Selecting Members

HHS Intentions on Tick-Borne Diseases Working Group Announced

Lyme Disease Association Announces that HHS Working Group Seeks Subcommittee Members



The new HHS Tick-Borne Disease Working Group (TBDWG) is seeking nominations from federal employees and members of the public who are interested in being considered for appointments to subcommittees being established to provide information for the TBDWG. **Nominations will be accepted until midnight on January 7, 2018.**

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1. Disease Vectors, Surveillance and Prevention (includes epidemiology of tick-borne diseases).
2. Pathogenesis, Transmission, and Treatment

3. Testing and Diagnostics (including laboratory-based diagnoses and clinical-diagnoses)
4. Access to Care Services and Support to Patients
5. Vaccine and Therapeutics
6. Other Tick-Borne Diseases and Co-infections

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From HHS: Submission Process and Deadline Nominations will only be considered from two sources: (1) nominations that are submitted by persons who would like to serve on the subcommittee and (2) follow up with persons who previously submitted their names for consideration as members of the full Working Group. Persons who are interested in serving on a subcommittee are invited to nominate themselves by submitting an email with the necessary information from the HHS website to tickbornedisease@hhs.gov. Nominations will be accepted until midnight on January 2, 2018.

See [HHS.gov](https://www.hhs.gov) and the Office of Assistant Secretary of Health for full details
<https://www.hhs.gov/ash/advisory-committees/tickbornedisease/notices/index.html>

Related links

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LDA President Appointed to HHS Tick-Borne Disease Working Group



The Lyme Disease Association (LDA) reports that the U.S. Department of Health and Human Services announced on November 22, 2017, the appointment of 14 members, 7 federal and 7 non-federal, to the new HHS Tick-Borne Disease Working Group. Lyme Disease Association President Pat Smith was one of 7 non-federal appointees to the Working Group, which was established through passage of the 21st Century Cures legislation. The purpose of the Working Group is to review all HHS efforts related to tick-borne diseases to provide expertise and help ensure interagency coordination and minimize overlap, examine research priorities and identify unmet needs.



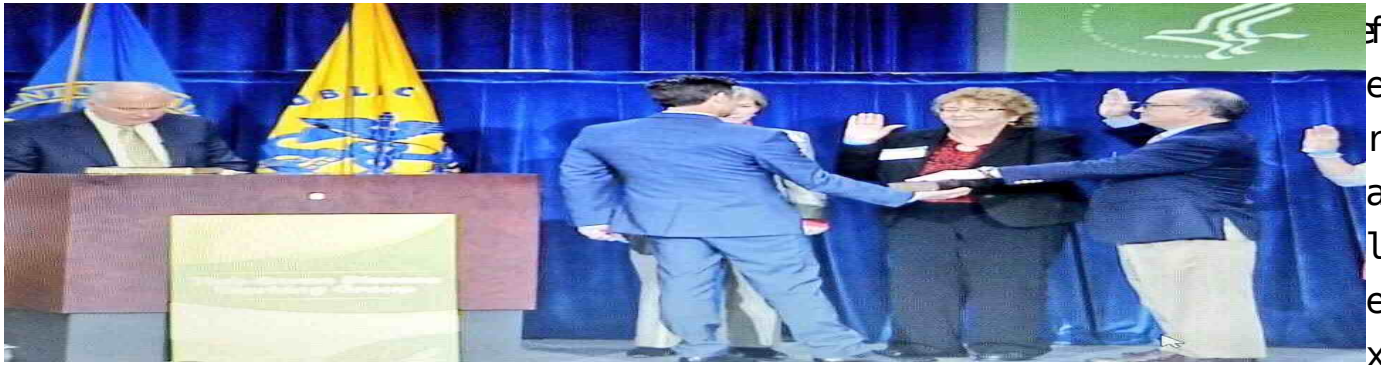
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ing Group Members, including Pat Smith, LDA Pres. (5th from L) The Lyme Disease Association (LDA) reports that the U.S. Department of Health and Human Services announced on November 22, 2017, the appointment of 14 members, 7 federal and 7 non-federal, to the new HHS Tick-Borne Disease Working Group. Lyme Disease Association President Pat Smith was one of 7 non-federal appointees to the Working Group, which was established through passage of the 21st Century Cures legislation.

The purpose of the Working Group is to review all HHS efforts related to tick-borne diseases to provide expertise and help ensure interagency coordination and minimize overlap, examine research priorities and identify unmet needs.

As per the establishing legislation, the Working Group consists of a diverse set of stakeholders, including physicians and other medical providers with experience in diagnosing and treating tick-borne diseases; scientists or

researchers with expertise in this field; patients and family members; patient advocates Pat Smith, LDA Pres. being sworn in to HHS TBDWG; and



experts who work in related areas.

The Working Group will hold its inaugural public meetings on Dec. 11, 2017, from 12:30 p.m. to 4:30 p.m. ET, and Dec. 12, 2017, from 9:00 a.m. to 4:30 p.m. ET, in the Great Hall of the Hubert H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C.

Signup for public to attend the meeting in DC or online, by December 8 ([click here](#))

HHS press release on the Working Group ([click here](#))

HHS Working Group Website ([click here](#))

Videos of Meetings 1 and 2 of the HHS Tick-Borne Disease Working Group ([click here](#))

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HHS Intentions on Tick-Borne Diseases Working Group Announced



The Lyme Disease Association announced that early today, July 14, the US Department of Health & Human Services (HHS) released its intent to establish the Tick-Borne Disease (TBD) Working Group called for in Section 2062 of the 21st Century Cures Act. The working group will assist HHS in its efforts to conduct and support epidemiological, basic, translational and clinical research related to vector-borne diseases, including tick-borne diseases. The working group will function as a Federal Advisory Committee and its activities will be overseen by HHS's Office of the Assistant Secretary for Health.

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Language to create the TBD Working Group was incorporated into the 21st Century Cures Act, thanks to the work of Congressman Chris Gibson, advocates, and Lyme Caucus Co-Chair Congressman Chris Smith who all carefully monitored the progress of the Lyme disease bill they supported that was introduced into the House in 2015 (HR 789 Gibson- NY). There was intense

grassroots lobbying efforts to ensure the language in the bill was beneficial to patients. Subsequently, some of that language was incorporated into the 21st Century Cures Act passed by the House. The Senate, however, wanted to write its own Cures Act and weakened that Lyme language, and the Lyme community had to fight to get it back. Successful negotiations with House Leadership were led by LDA President Pat Smith and a team of advocates to have the stronger language reinstated into 21st Century Cures, which enabled the Working Group to have a seat at the table for some of the most important stakeholders: patients/advocates and treating physicians.

The working group's mission will be to review all the efforts within HHS related to tick-borne diseases, to examine research priorities, to help ensure interagency coordination and to minimize overlap. The working group will be made up of representatives from both federal and non-federal agencies and entities.

HHS is seeking nominations for non-federal members through August 15, 2017. Information is available in the Federal Register

Notice:

<https://www.federalregister.gov/documents/2017/07/17/2017-14965/requests-for-nominations-tick-borne-disease-working-group>

In other information from Washington, DC, the House passed HR 2810 authorization for appropriations for fiscal year 2018 for military activities of the Department of Defense. It contained an amendment from US Representative Bill Keating (MA) that permits the DOD to partner with medical researchers and universities to test for tick-borne illnesses.