



PO Box 1352 ♦ Chico CA 95927 ♦ 530-899-1587 ♦ info@lymedisease.org

Captain Richard Henry
Office of HIV/AIDS and Infectious Disease Policy
Office of the Assistant Secretary for Health
U.S. Department of Health and Human Services (HHS)
330 C Street, SW
Room L001, Switzer Building
Washington DC, 20201

August 13, 2017

Re: Position Statement Regarding Patient Representation Nominations to the HHS Tick-Borne Disease Working Group

Dear Captain Henry and HHS Selection Committee:

The undersigned advocates and representatives of the Lyme and tick-borne diseases community are advising you that the American Lyme Disease Foundation (ALDF) does not represent patients. We respectfully request that you not award that organization any of the spaces reserved for patients on the federal Tick-Borne Working Group established by the 21st Century Cures Act.

The ALDF represents the interests of researchers affiliated with the Infectious Diseases Society of America (IDSA). Yet it portrays itself to the press and others as a patient organization. Before joining the ALDF, its president, Dr. Phil Baker, headed the NIH Lyme research efforts and notoriously referred to Lyme patients as “Lyme loonies.”

The ALDF website recommends the IDSA’s Lyme diagnostic and treatment guidelines, while ignoring those of the International Lyme and Associated Diseases Society (ILADS), the first evidence-based guidelines graded according to Institute of Medicine standards and the only guidelines currently listed on the National Guidelines Clearinghouse website.

In 2006, then-Attorney General of Connecticut Richard Blumenthal conducted a civil investigation of the IDSA for anti-trust violations. He found serious flaws in its guidelines process and that many of its authors had conflicts of interest. The ALDF board of directors consists of nine members. Four were members of the IDSA 2006 Lyme guidelines panel and two were included in the acknowledgments to the guidelines. The IDSA recommendations for Lyme disease fail far too many patients, leaving them ill.

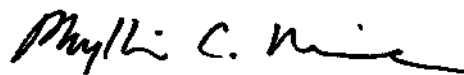
The ALDF website contains an endorsement from an IDSA journal (*Clinical Infectious Diseases*) that states: “The best private organization-based site that can be recommended to patients for education on Lyme disease is that of the American Lyme Disease Foundation.” Unfortunately, the press has been quoting the ALDF’s message that Lyme is hard to catch, easy

to diagnose, easy to treat, and that chronic Lyme does not exist. Furthermore, academic presentations also refer to ALDF as a prime source for patient information.

The ALDF is not a grassroots patient organization. It represents vested commercial interests of the IDSA. It does not represent patients.

As real grassroots support groups representing real patients with Lyme disease, we want to make clear that the ALDF does not represent the interests of people with Lyme and other tick-borne diseases. We regard the ALDF's positions and statements regarding Lyme disease as harmful to patients. Thank you for your consideration.

Sincerely yours,



Phyllis Mervine, Founder and President, LymeDisease.org

Pat Smith, President, Lyme Disease Association, NJ

Scott Santarella, Executive Director, Global Lyme Alliance, CT

Linda Giampa, Executive Director, Bay Area Lyme Foundation, CA

Karen Gaudian, Co-Chair, LymeConnection.org, CT

Jill Auerbach, Chair, Hudson Valley Lyme Disease Association, NY

Julie Merolla, Director, LDA Rhode Island Chapter, RI

Christina Fisk, President, Lyme Action Network, NY

Robert Bonine, President, Minnesota Lyme Disease Association, MN

Monica White, President/Co-Founder, Colorado Tick-Borne Awareness Association, CO

Doug Fearn, Chair, Lyme Disease Association of Southeastern Pennsylvania, PA

Michele Miller, Co-Founder, Central Massachusetts Lyme Foundation, MA

Michelle Louie, President, Arizona Lyme Disease Association, AZ

Teresa Lucher, President, Texas Lyme Disease Association, TX

Ila Utley, President, Lyme Disease Association of Greater Kansas City, KS

Sheila Statlender, PhD, Chair, Massachusetts Lyme Legislative Task Force, MA

Melissa Bell, President, Florida Lyme Disease Association, FL

Alicia Cashman, Director, Madison Lyme Support Group, WI

Sherrill Franklin, Director, Lyme Research Initiative, PA

Sharon Lee, Co-Leader, Southern Oregon Lyme Disease, OR

Vicki Petsy, President , Kentucky Lyme Disease Association, KY
Kevin Wolfe, President/CEO, Alabama Lyme Disease Association, AL
Linda Reilly, Director , Mid Shore Lyme Disease Association, MD
Scott Morris, Director , Long Island Lyme Association, NY
Robert Sabatino, Founder/Executive Director, Lyme Society Inc., NY
Sherry Stevewright, President, Wisconsin Lyme Network, WI
Colleen Schake, Founder, Lyme Disease Coalition, PA
Cindy Casey, RN, Director, Charles E. Holman Morgellons Disease Foundation, TN
Amy Tiehel, Founder, Pennsylvania Lyme Resource Network Delco Region, PA
Nancy Bourassa, President, Lyme 411, NH
Phyllis Bedford, Executive Director, LymeLight Foundation, CA
Karla Lehtonen, Leader, Lyme Alliance of the Berkshires, MA
Karen Angotti, Director, Memphis Tennessee Lyme Network, TN
Alison Childs, Director, Lyme Stats, CA
Linda Wales, Director , A Hope for Lyme, NY
Margaret Smith, President, Southern Tier Lyme Support Inc., NY
Robert Stibitz, Co-Chair, York Lyme Disease Support Group, PA
Jean Ann Redman, Director, Valley Lyme Support Group of Bradford County, PA
Michelle Cassetori, Leader, NEPA Lyme Disease Support Group, PA
Valarie Murphy, Director, Colorado Lyme Group North, CO
Elizabeth Naugle, Co-Moderator, TXLyme, TX
Ellen Lubarsky, Leader, New York City Lyme Disease Support Group, NY
Rebecca Roll, Co-Chair, Lyme WNY, NY
Paula Jackson Jones, President/ Co-Founder, Midcoast Lyme Disease Support & Education, ME
Shelly Walker, Co-Leader, Mendocino County Lyme Disease Support Group, CA
Jeffrey Dugas, Director, Brookfield/Wolfeboro NH support group, NH
Theresa Morehouse, Founder, Ithaca Area Lyme Support Group, NY
Margaret Leone-Smith, Founder/ President, Southern Tier Lyme Support, NY
Bill Moore, Leader, Pittsburgh Lyme Disease Support Group, PA

