



# *Lyme Disease Association, Inc.*

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[www.LymeDiseaseAssociation.org](http://www.LymeDiseaseAssociation.org)

April 27, 2015

Child Neurology Society (CNS)

Attn: Nina F. Schor, MD, PhD, President

[nina\\_schor@urmc.rochester.edu](mailto:nina_schor@urmc.rochester.edu)

Dear Dr. Schor,

I am writing on behalf of the Lyme Disease Association, Inc. and LymeDisease.org and the total 89 undersigned organizations to share concerns we have about the process in which you are a partner organization with the Infectious Diseases Society of America (IDSA)—i.e., the revising of the Lyme disease treatment guidelines.

As representatives of Lyme disease groups across the U.S., we want to ensure that you understand the perspectives of these organizations who represent the viewpoints of hundreds of thousands of patients who either have Lyme disease or have close family members/friends with the disease. In addition, several of these organizations fund research on Lyme and other tick-borne diseases (TBD) much of it published in peer review and have sponsored CME conferences on TBDs.

The history of prior IDSA Lyme disease guidelines' iterations has been contentious from the patient perspective. Patients have repeatedly asked to be involved in the guideline development process for these guidelines, which profoundly impact their ability to obtain access to care. Patients have also requested that a broad spectrum of scientific and clinical viewpoints be represented at the table. The current guidelines development process continues to exclude viewpoints from patients and from clinicians who treat most of the patients who fail a single course of antibiotic treatment—often some of the sickest people who require the highest level of medical care. It also excludes researchers who hold viewpoints that are not aligned with those of the IDSA.

We submitted comments to the IDSA following all the rules during the open comment period, which originally ended April 9. Part of our comment addressed the short length of the comment period itself, which included two major holidays. IDSA closed the comment period on the 9<sup>th</sup> before close of business, then without notice, reopened the next day, extending the time period until April 24.

After the extension notice appeared, we wrote to IDSA and requested the right to send additional comments with additional signers, since the opportunity to complete both tasks was not optimal under the original time period, and we had no idea an extension after the fact would be offered. We were denied, with IDSA indicating in an email that the rule was that the submission had to be completed in one sitting. Of course that “one-sitting submission” rule applied under the original “4-week deadline” rule, the latter which was subsequently changed—thus, had the IDSA embraced a desire to reasonably accommodate input from scores of advocacy organizations representing many thousands of patients, we should have been permitted to submit additional material and additional signers.

Since we have no knowledge of IDSA's intent with respect to comment dissemination to any of its partners, along with this cover letter, we include the comments we sent to IDSA, and additional comments submitted by other groups who would have signed onto our comments and do endorse our comments. We also endorsed the comments of these groups. They tried to submit their comments during the extended period, but it was closed out before they could do so.

We also draw your attention to the fact that LDo conducted a survey of patients to determine what outcomes patient deem important, as both the GRADE process and the IOM guidelines standards view this information as critical to the development process. [The report on this survey](#), which drew over 6,100 responses in one month, is now available for you to review.

We respectfully ask that you examine the materials we have submitted, review our concerns from the patient perspective, and further investigate the issues we have raised. Our goal, and we are confident, your goal, is to ensure that patients who are treated for Lyme disease are given the best possible medical care to bring them toward a state of health.

Do not hesitate to contact me with any questions.

Thank you.

Sincerely,

Patricia V. Smith



President, Lyme Disease Association, Inc.

Lyme Disease Association, Inc., NJ

Lyme Disease.org, CA

Indiana Lyme Connect, IN

WA Lyme Fighters, WA

Gear Up for Lyme, VT

The Lyme Association of Greater Kansas City, KS

Kentuckiana Lyme Disease Support Group, KY

Greater Manchester Lyme Disease Support Group, NH

Bedford Lyme Disease Council, NH

MissouriLyme, MO

Illinois Lyme Group, IL

Journey Through Challenge, PA

Brookfield/Wolfeboro Lyme Support Group, NH

Greater St Louis Lyme-Masters Disease Support Group, MO

Mid-Shore Lyme Disease Association, Inc, MD

Lyme Disease Eugene Oregon, OR

Military Lyme, CO

Cfsfml, CO

Lyme Action Network, NY

TXLDA, TX

Hudson Valley Lyme Disease Association, NY

Lyme Connection/RLDTF, CT

Lyme Alliance of the Berkshires, NY

Mid Missouri Lyme Support Group, MO

United Lyme Action, CA

New York City Lyme Disease Support Group, NY

Missouri Lyme, MO

MN Lyme Association, MN

Lyme Disease Assn. of Southeastern Pennsylvania, Inc., PA

LYME411, NH

Lyme Disease Seattle WA Organization, WA

Oregon Lyme Disease Network, OR

Central Mass Lyme Foundation, MA

Massachusetts Lyme Legislative Task Force, MA

Lyme Disease Education & Support Groups of Maryland, MD

Harford County Lyme Disease Support Group, Inc., MD

Central Maryland Lyme Disease Support Group, MD

National Tick-Borne Disease Advocates, TX

Michigan Lyme Disease Association, MI

LDA RI Chapter, RI

Madison Lyme Support Group, WI

Arizona Lyme Disease Association (AzLDA), AZ

Bergen Bowmen, NJ

Iowa Lyme, IA

Wisconsin Lyme Yahoo, WI

Newtown Lyme Disease Task Force, CT

Lyme Disease Support Group of Southwestern Vermont, VT

Professional Research Center of Naples, FL

Arklatex Lyme Disease Prevention & Support, TX

Clarksville Lyme Support, TN

Lyme Disease Support, WY

Greater Boston Area Metro West Lyme Disease Suprt. Grp., MA

Ticked Off On Lyme WA, WA

National Capital Lyme Disease Association, VA

Greater Danbury Lyme Disease Support Group, CT

Kentucky Lyme Disease Association (KyLDA), KY

Sturbridge Lyme Awareness of MA (S.L.A.M.), MA

Utah Lyme Disease Alliance, UT

New Hampshire Lyme Alliance, NH

MaineLyme, ME

Mid Missouri Lyme support group, MO

IGeneX, Inc., CA

PALRN (PA Lyme Resource Network) Delco Region, PA

Massachusetts Lyme Coalition, MA

The Charles E. Holman Morgellons Disease Foundation, Nursing  
Advisory Panel, TN

Eastern Ct Chapter, Lyme Disease Association, CT

Florida Lyme Disease Association, FL

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**”Extension Signers”**

LymeQuest Support Group & Advocacy Project, NJ

Bristol County, MA Lyme Support Group, MA

LymeCareNow, NY

Lyme Disease Network of Middle Tennessee, TN

Portland Lyme Disease Support Group, OR

Children's Lyme Disease Network, NY

Bluegrass Lyme Support, KY

Alabama Lyme Disease Association, AL

Los Angeles Lymie Group, CA

TICKED OFF, MA

Pennsylvania Lyme Group FB, PA

The Lyme Disease Group, PA

Indiana Lyme, IN

Wisconsin Lyme Network, WI

World Lyme Day, ON

Cortland County Lyme Disease Support Group, NY

SF SEAL-San Francisco Support, Education & Advocacy for  
Lyme, CA

Lyme Aid-Santa Rosa, CA

American Lyme Association, CA

The Mayday Project, VA

Lyme Nation, NY

Georgia Lyme Disease Connection, GA