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NatCapLyme Submitted Its Response to the IDSA Regarding Their Updated Lyme Disease Guidelines During the Public Comment Period

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The National Capital Lyme Disease Association (NatCapLyme) is submitting this letter as the organization's official response to the Infectious Diseases Society of America's (IDSA) public comment period regarding its draft of their updated Lyme disease guidelines.

Before addressing the guidelines, we would like to comment on the format in which the IDSA provided access to the draft guidelines for review. Specifically, while the document was posted online, the IDSA restricted the ability to download or print the document, thereby requiring the reviewer to read the entire publication online. To expect a reader to fully analyze such a comprehensive and complex document ONLY online was an obvious ploy by the IDSA to make the review of this material as difficult as possible. The Lyme community sees through this disingenuous behavior, as did *Forbes Magazine*, which published an article on the proposed draft guidelines. After the IDSA denied a request from *Forbes* and the article's author to receive a PDF version of the draft guidelines, the author wrote, ["Their refusal makes me feel they really don't want people to comment on their 81-page draft and 203 page supplement."](#) Engaging in such underhanded behavior distracts from their transparency and greatly harms the relationship with the Lyme community and reinforces the belief that the IDSA is not in touch with or cares about the growing number of patients suffering from Lyme and other tick-borne diseases.

Regarding the proposed updated guidelines, there appear to be only minor changes from the IDSA's previously published and decades old guidelines. The new draft is still based on outdated and, in some cases, discredited studies. Patient groups have clearly demonstrated that thousands who suffer from Lyme and associated tick-borne diseases are losing their battle for health and the pursuit of happiness due to the failure of our national and professional institutions to address this growing epidemic in any meaningful way. To paraphrase the great physician, philosopher and scientist Moses Maimonides: there is no point to science without progress.

Meanwhile, the Centers for Disease Control and Prevention (CDC) and National Institutes of Health (NIH) continue to divert their focus to the highly dubious goal of creating a vaccine before developing a reliable test for Lyme or classifying all the

strains of the disease. Without these prerequisite measures, the production of an effective vaccine is significantly compromised. Of course, NatCapLyme would like to see a “safe and effective” vaccine brought to market. However, the current effort narrowly focuses on a few strains of *Borrelia* in a rush to certify a vaccine. This offers only a limited public-health benefit and harbors a serious potential health risk by suggesting to those vaccinated that they are protected from all strains of Lyme and co-infections.

NatCapLyme is a nationally recognized Lyme advocacy organization that continues to hold face-to-face support group meetings. We also have a telephone hotline to take calls from those seeking help regarding Lyme and tick-borne diseases, and each day we are on the phone for hours providing information, references and support. While the IDSA continues to stand behind outdated and biased research, we see and hear what is really happening across America. Standing on the front lines of this growing health epidemic, we are told the same story time and time again. At staggering rates, patients report being misdiagnosed, inadequately treated, or worst of all, dismissed by the medical community as “hypochondriacs.” In reality many of these individuals have real bacterial, viral, or parasitic infections ravaging their bodies resulting from a tick bite. Children, who are most at risk, are losing their childhoods and may spend their entire lives chronically ill, never to appreciate one day of good health or happiness. Once healthy adults are losing their livelihoods, because they are now too sick to continue working. Families are bankrupted by escalating medical costs as they try to find an answer to their multi-systemic symptoms and illness. A 2015 research study published by the Johns Hopkins Bloomberg School of Public Health found that Lyme disease costs the U.S. health care system between \$712 million to \$1.3 billion to treat each year. Again, we are only talking about Lyme disease, not other co-infections. Add to that the indirect costs, such as lost wages and taxes, and the total cost of Lyme disease is in the billions each year.

NatCapLyme sees that the updated Lyme disease guidelines proposed by the IDSA are just status quo and woefully inadequate to address the true extent of the tick-borne disease epidemic reeking havoc across the U.S. With an estimated 427,000 new cases of Lyme disease contracted each year, as published by the CDC, and with little progress in the identification, diagnosis and treatment of tick-borne illnesses, NatCapLyme believes that an increasing number of people will become infected and may subsequently remain sick perhaps indefinitely. In reality, thousands of U.S. citizens are being stricken with a potentially life-long debilitating medical condition that is not, or is barely, recognized by the IDSA. Based on the proposed draft guidelines, we believe that the status quo will be perpetuated for years to come. Tick-borne illness, especially in the chronic form, will continue to be discounted by the vast majority of physicians, government policy makers and researchers as the IDSA clings to the belief that Lyme disease is hard to catch and easy to treat.

Unfortunately, the Lyme community’s past experience with the IDSA demonstrates the serious challenge of achieving significant change. Little progress is made when a

professional medical society that promulgates guidelines to diagnosis and treat tick-borne diseases only recognizes and supports the same old cast of researchers who repeatedly test the same old ideas. In an article published by the *Washington Post* titled ["Why we shouldn't take peer review as the 'gold standard,'"](#) **Word did not find any entries for your table of contents.** it states that, "peer review can act as a shield to protect the status quo and suppress research viewed as radical or contrary to the established perspectives of referees." Moreover, "groundbreaking studies by Sir Frank MacFarlane Burnet, Rosalind Yalow, Baruch Blumberg and others were rejected by peer reviewers, yet later led to Nobel Prizes."

We believe that the key to any progress lies in advancing research in all aspects of the diseases, especially in the development of better diagnostic tools for the detection of all tick-borne diseases. Clearly these guidelines do not do that. We appeal to the IDSA and the research community to expand its focus on emerging and promising research that comes from fresh and new perspectives. It should bring together the best minds and best theories of ALL parties, and require that ALL theories be examined and considered. NatCapLyme believes that true solutions to the dilemma of Lyme and tick-borne infections may be found only when all parties are willing to consider the view that each party holds. Perhaps if we all work together we can forever end this terrible pandemic.

In conclusion, NatCapLyme in no way endorses the adoption of the IDSA's updated Lyme disease guidelines. The patient community is extremely angry about the lack of scientific and medical progress with respect to Lyme and our masses are growing by the tens-of-thousands each year. This problem is not going away until all parties are invested in creating real solutions that benefit all patients, and society as well. Despite being sick, in pain, exhausted, frustrated and financially drained, we are committed to this cause and will not stop until we regain our health, halt this epidemic, and ensure that these terrible tick-borne diseases do not burden future generations.