

Lyme Disease Patient Surveys

[Real Lives. Real Stories. From the IDSA Lyme survey.](#)

REAL LIVES. REAL STORIES.



Our March 2015 patient survey drew over 6,100 responses. Survey results were incorporated into our formal submission to the Lyme guidelines panel of the Infectious Diseases Society of America. We will also share this information with lawmakers, health officials, and journalists. [Click here to read the results.](#)

Too often, healthcare policy makers are unaware of the many ways that Lyme disease seriously affects patients, their families, their communities, and ultimately the whole nation. In order to bring the perspective of Lyme disease patients to the forefront, we conduct nationwide surveys of Lyme patients. We share that information with lawmakers, journalists, and others in the healthcare arena. We give voice to the Lyme patient community.

In January, 2015, we conducted a survey on the Food and Drug Administration's proposed restrictions on Lyme testing. We included survey results when we talked to the FDA about how much the proposed regulations would harm Lyme patients.



The results of two earlier surveys have been published in peer-reviewed journals.

The first one, looking at access to care and burden of illness was published in Health Policy in 2010. It revealed that 65% of patients with chronic Lyme disease have had to cut back or quit work or school and 25% have been on disability.



The second one, published in PeerJ in 2014, [examined health-related quality of life](#) using standard Health Related Quality of Life questions from the Centers for Disease Control and Prevention. It found that chronic Lyme disease is associated with a worse quality of life than most other chronic illnesses, including congestive heart failure, diabetes, multiple sclerosis and arthritis.



Resources:

- Johnson L, Wilcox S, Mankoff J, Stricker RB. [Severity of chronic Lyme disease compared to other chronic conditions: a quality of life survey.](#) PeerJ. 2014 2014/03/27;2:e322. This study is available open access (free of charge).
- Read the Lyme Policy Wonk blogs summarizing the results of the study:
- [Survey Results Published! Chronic Lyme Patients Suffer Poor Quality of Life and High Rates of Disability and Unemployment](#)
- [Study Finds Coinfections in Lyme Disease Common](#)
- [The IDSA Says Chronic Lyme Disease Is No More than the Aches and Pains of Daily Living. Is this True?](#)
- [Chronic Lyme disease patients suffer high unemployment and disability](#)
- [How many of those with Lyme disease have the rash? Estimates range from 27-80%](#)
- Read the Lyme Policy Wonk blog summary of the results of "[Healthcare access and burden of care for patients with Lyme disease: a large United States survey.](#)" Health Policy 102(1): 64-71.) (This is not available open access; the publisher charges a fee.)
- Watch a [presentation](#) of the findings of the Healthcare Access and Burden of Care Survey by LymeDisease.org CEO, Lorraine Johnson, JD, MBA at the forum hosted by US

Congressman Gibson in New York on May 21, 2012 or read a Lyme Policy Wonk blog [summary of the presentation](#).