

## WHY WE PROTEST AGAINST THE IDSA

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

The Centers for Disease Control and Prevention (CDC) recently made headlines by releasing new estimates of how many people catch Lyme disease every year. They increased the number ten-fold, from 30,000 to 300,000. However, nothing has changed about how Lyme disease is diagnosed and treated. Or, more often, NOT diagnosed and NOT treated.

Untold thousands of Lyme patients across the United States are denied access to appropriate medical care because the CDC promulgates Lyme treatment guidelines put forth by the Infectious Diseases Society of America (IDSA). The IDSA is a private medical association that doesn't have to answer to anybody. The CDC is a federal agency that essentially allows the IDSA to set its policy regarding Lyme disease.

Medical treatment guidelines are tremendously important. Guidelines for most diseases are listed by the National Guidelines Clearinghouse (NGC), which is part of the US Department of Health and Human Services. It's the government's way of providing updated information to health care professionals. Doctors consult guidelines to determine how best to treat their patients and insurance companies use them to decide what treatments to pay for.

**IDSA LYME GUIDELINES MISREPRESENT SCIENCE AND RESTRICT ACCESS TO CARE**  
The IDSA defines the illness so narrowly that many people otherwise determined to have Lyme disease are denied access to medical care. Even those given treatment are usually limited to a "standard course" of antibiotics (often 2-3 weeks) even when they remain ill. Furthermore, insurance companies often won't pay for anything beyond what's stipulated in the guidelines.

- \* They state that only "a few" patients remain ill after standard treatment while the true figure is 25 to 50 percent. (Stricker & Johnson 2011)

- \* They say the NIH-funded trials prove definitively that longer treatments are not effective **DESPITE THE FACT** that only four such human studies have been conducted, **DESPITE THE FACT** that two of the studies showed improvement on treatment, and **DESPITE THE FACT** that the sample populations in each of the

treatment trials was small and did not reflect patients seen in clinical practice. (DeLong et al. 2012, Fallon et al. 2012) Fallon's evaluation of the four trials concludes that "approximately 60% of patients with persistent post-treatment Lyme fatigue may experience meaningful but partial clinical improvement in fatigue with antibiotic retreatment."

- \* Two recent studies by members of the IDSA have found that the majority of the recommendations in the IDSA guidelines are based more on "expert opinion" than on scientific evidence. (Khan et al. 2010; Lee et al. 2011; Johnson & Stricker 2010a).

- \* Forty percent of the studies cited are written by the authors of the guidelines, who ignore other studies that don't support their viewpoint. (Johnson & Stricker 2010a).

#### EXAMPLES OF OUTDATED ASSERTIONS THAT HURT LYME PATIENTS

- \* IDSA guidelines claim that a) persistence of the Lyme spirochete after treatment is "not plausible," b) antibiotic treatment is ineffective for chronic Lyme, and c) single-dose antibiotic is effective to prevent Lyme. (Wormser et al. 2006). All of these assertions have been discredited in subsequent monkey and mouse model trials.

- \* Subsequent monkey and mouse studies have found persistence of Lyme spirochetes after treatment, even after 90 days of treatment. (Embers et al. 2012).

- \* The monkey trial found that antibiotics were effective and cleared spirochetes 25% of the time when treated for 90 days.

- \* IDSA guidelines rely heavily on a single human trial conducted by one of the guidelines authors (Klempner 2004), which has subsequently been found to be statistically flawed. (DeLong et al. 2012).

- \* IDSA's own guideline review panel recommended over 25 modifications to the guidelines, which have not been incorporated into the guidelines. (IDSA 2010).

- \* In 2008 the IDSA adopted a rigorous evidence assessment process, which has not been applied to the Lyme guidelines. (IDSA 2011).