

There is considerable uncertainty in the diagnosis and treatment of Lyme disease—particularly persistent Lyme disease. Most patients know that they should be told of the risks and benefits of the different diagnostic and treatment options available and allowed to determine the best approach in collaboration with their physician for individualized care.

## Shared Medical Decision-Making in Lyme Disease Treatment

This process is called *shared medical decision-making* and is most often used when science is uncertain and trade-offs exist between the benefits and risks, as well as among the quality-of-life consequences of different treatment approaches. Think of prostate cancer, where patients and their physicians choose from watchful waiting, radiation therapy, hormone therapy, and surgery.

Government agencies, including the FDA, the Institute of Medicine, the Patient-Centered Outcomes Research Institute (PCORI), and Medicare, support shared medical decision-making. LymeDisease.org believes that this is essential for effective Lyme disease treatment.

Current diagnostic testing for Lyme disease cannot distinguish between active infection and cure.

The NIH has funded only three treatment studies for persistent Lyme disease—and the most

recent occurred more than 15 years ago. This poor evidence base leaves doctors and patients uncertain about the best way to diagnose and treat the disease.

## Two Standards of Care



Out of this uncertainty, healthcare professionals use two medically recognized standards of care for diagnosis and treatment. Both are reflected in peer-reviewed published guidelines — one by the International Lyme and Associated Diseases Society and the other by the Infectious Diseases Society of America. The ILADS guidelines adhere to the recommendation of the Institute of Medicine and follow the rigorous Grading of Recommendations, Assessment, Development, and Evaluations (GRADE) evidence assessment standards — which also embrace shared decision-making.

# IDSA

## Infectious Diseases Society of America

The main difference between the IDSA and ILADS guidelines—in the face of scientific uncertainty—is that the ILADS guidelines defer to clinical judgment and shared medical decision-making in the context of providing individualized care, whereas the IDSA guidelines severely restrict the use of clinical judgment and leave patients without treatment options when short-term therapy fails, as it does in far too many cases. Less than 10% of patients with persistent Lyme disease choose to be treated under IDSA protocols.

Accordingly, LymeDisease.org urges that the Working Group’s report recommend the following:

- that government agencies provide unbiased information regarding both standards of care;
- that physicians inform patients about the risks and benefits of different treatment options in the context of shared medical decision-making and individualized care; and
- that insurance reimbursement be available for treatment under either standard of care.

Today’s patients cannot wait for

## tomorrow's research!

Click the following link to read Johnson's full comments: [LBJohnson, TBDWG written comments](#).

Click the following link for a copy of [Informed-consent-for-Lyme-treatment](#).

Editor's note: Any medical information included is based on a personal experience. For questions or concerns regarding health, please consult a doctor or medical professional.