

10 things you should know about new IDSA guidelines

<https://www.lymedisease.org/10-things-new-idsa-guidelines/>

1. **There was no representation of chronic Lyme patients on the guideline panel.**

The IDSA says that the panel had “three patient representatives.” But the IDSA will not tell us their names. Representation needs to authentically reflect the patient community interests. It needs to be meaningful rather than token.

2. **The guidelines do not provide for shared-medical decision-making despite their lip service to the contrary**
3. **The IDSA guidelines do not use treatment outcomes important to patients as GRADE requires.**
4. **The IDSA guidelines set the evidence bar too high by requiring that studies be done before any treatment is appropriate.**
5. **Patients who don't present with objective signs of early Lyme (an erythema migrans rash or Bell's palsy) will have a difficult time getting diagnosed.**
6. **Patients who don't present with objective signs of late Lyme disease or neuroborreliosis will have a difficult time getting diagnosed.**

The guidelines strongly recommend against “routine” testing for disease in patients with:

- Typical amyotrophic lateral sclerosis (ALS),
- Relapsing-remitting multiple sclerosis (MS),
- Parkinson's disease,
- Dementia, or cognitive decline,
- New-onset seizures,
- Psychiatric illness, and
- Children with developmental disorders.

7. **Retreatment for early and late Lyme disease is very restrictive generally because the possibility of persistence of infection is denied across the board.**

8. **The treatment for early EM rash or flu-like symptoms is limited to 10-14 days of treatment.**
9. **Chronic Lyme disease and persistent infection do not exist or at least should not be treated.**
10. **The guidelines make no recommendation for or against the use of antibiotics to treat STARI—specifically say “no recommendation; knowledge gap.”**

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