

Lyme Disease: Financial Burden of Illness



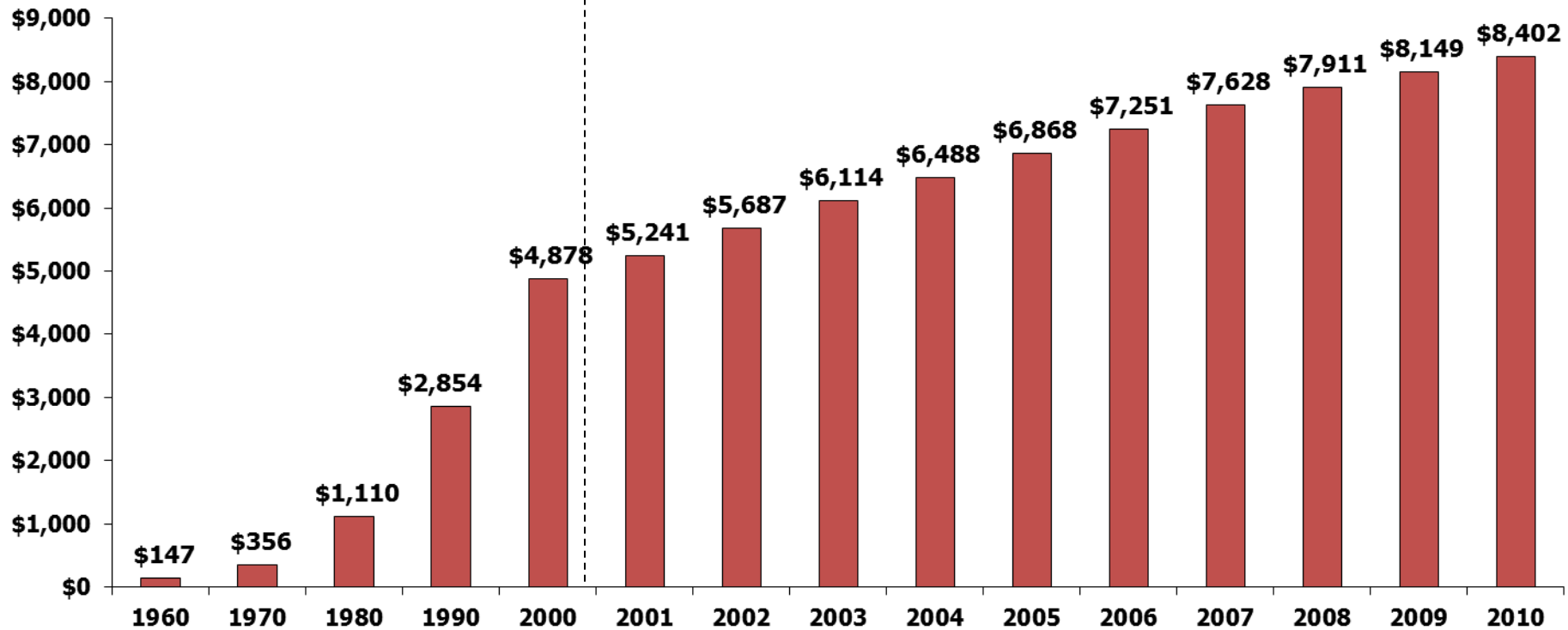
Lorraine Johnson, JD, MBA

CEO LymeDisease.org

Board Member ILADS

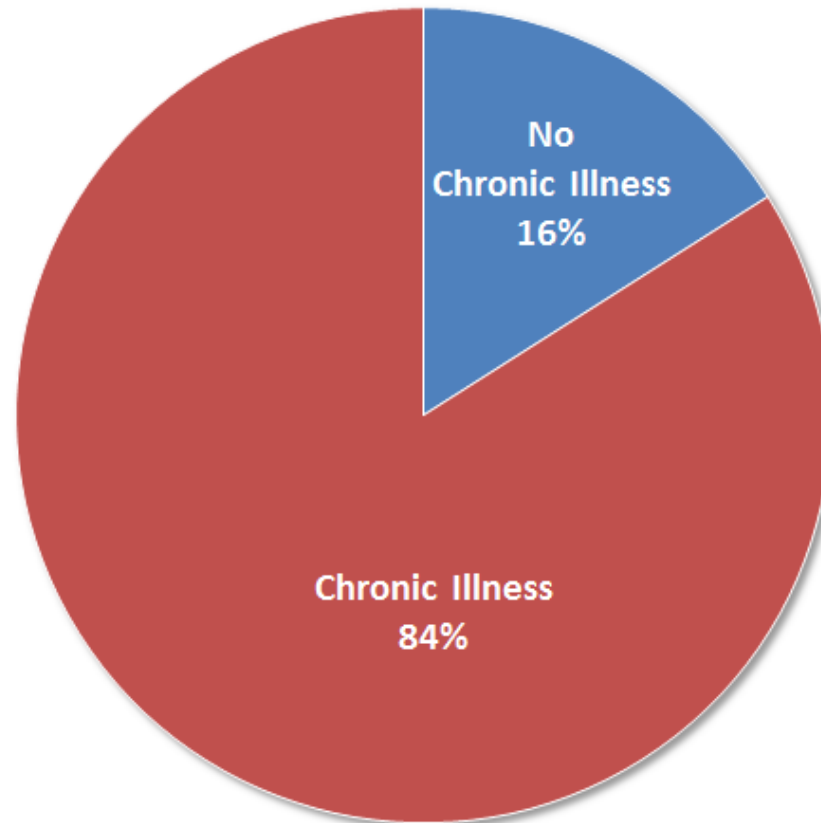
Steering Committee, Consumers United for Evidence-Based Healthcare

US Health Expenditures per Capita 1960-2010



Healthcare costs have doubled over the past 10 years.

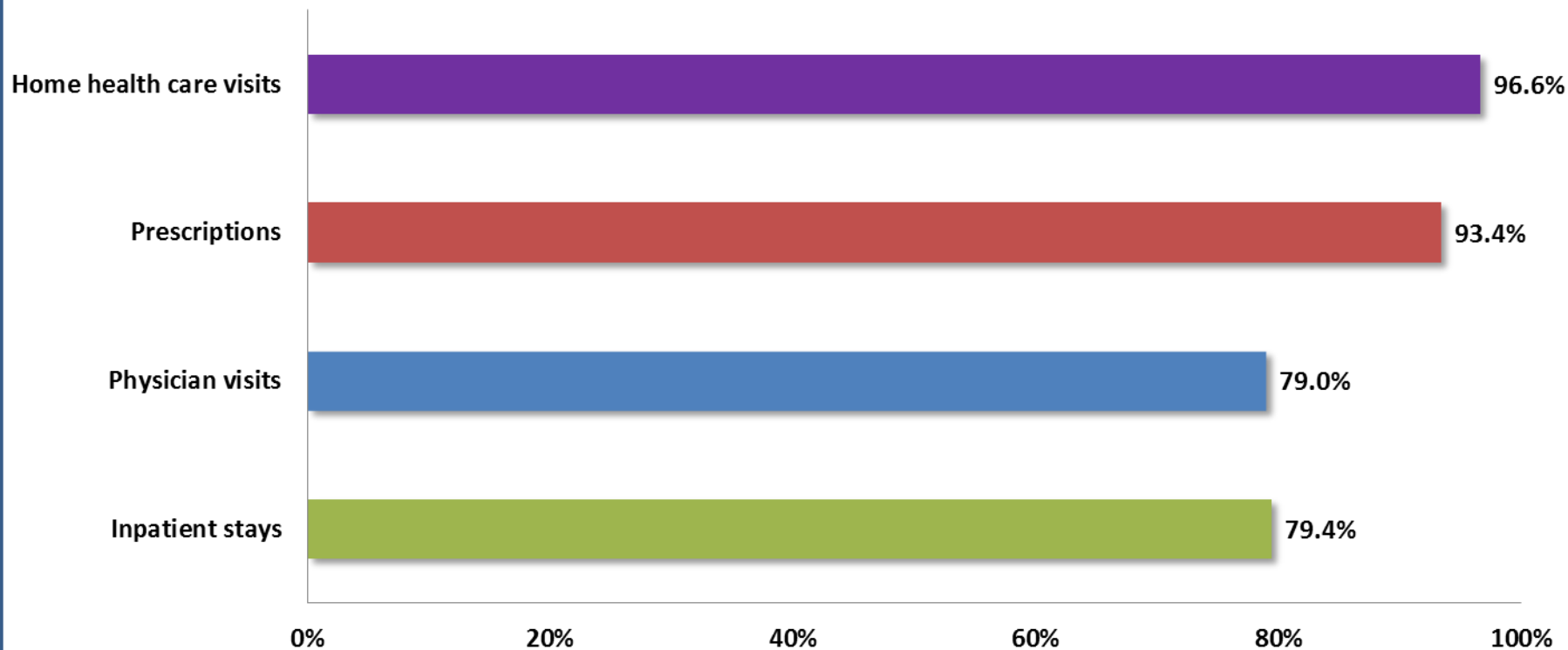
Chronic Conditions HealthCare Spending



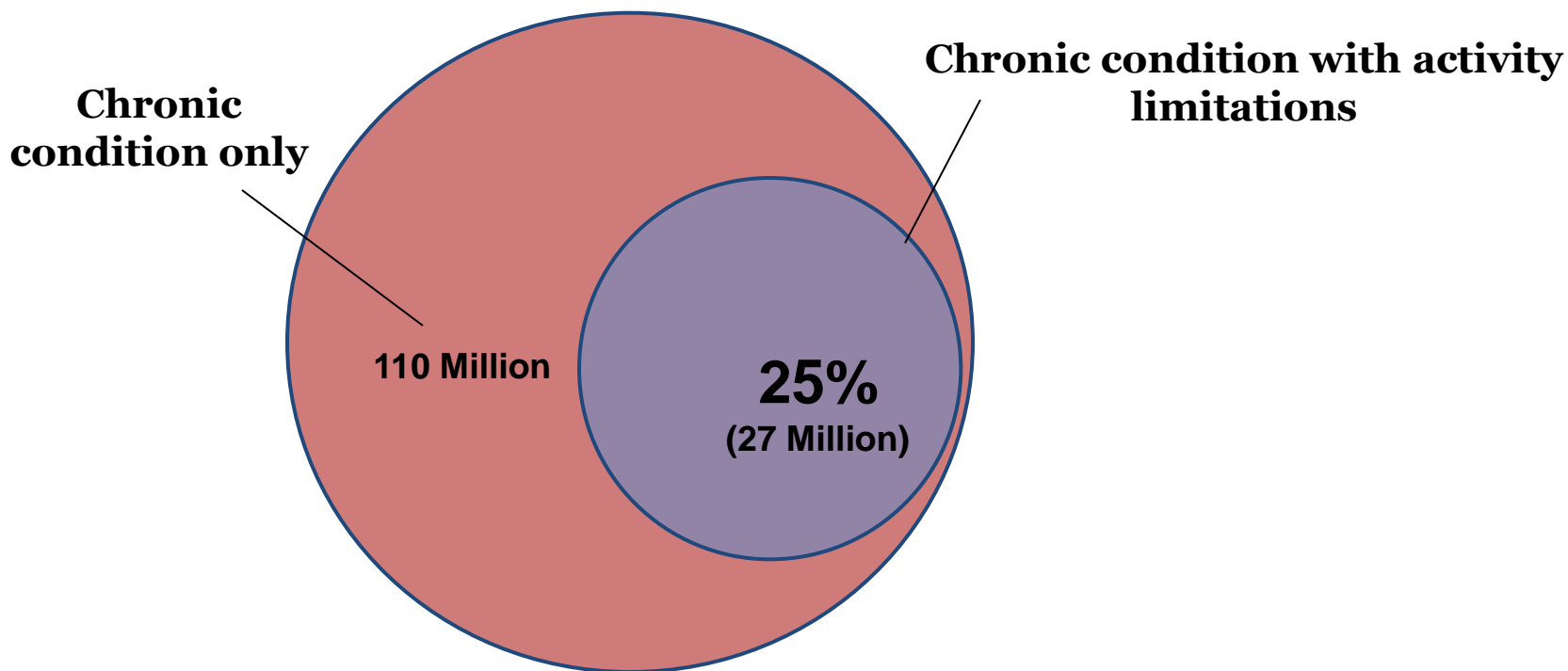
Chronic illness accounts for 84% of healthcare costs.



Those with Chronic Conditions are the Heaviest Users of Healthcare

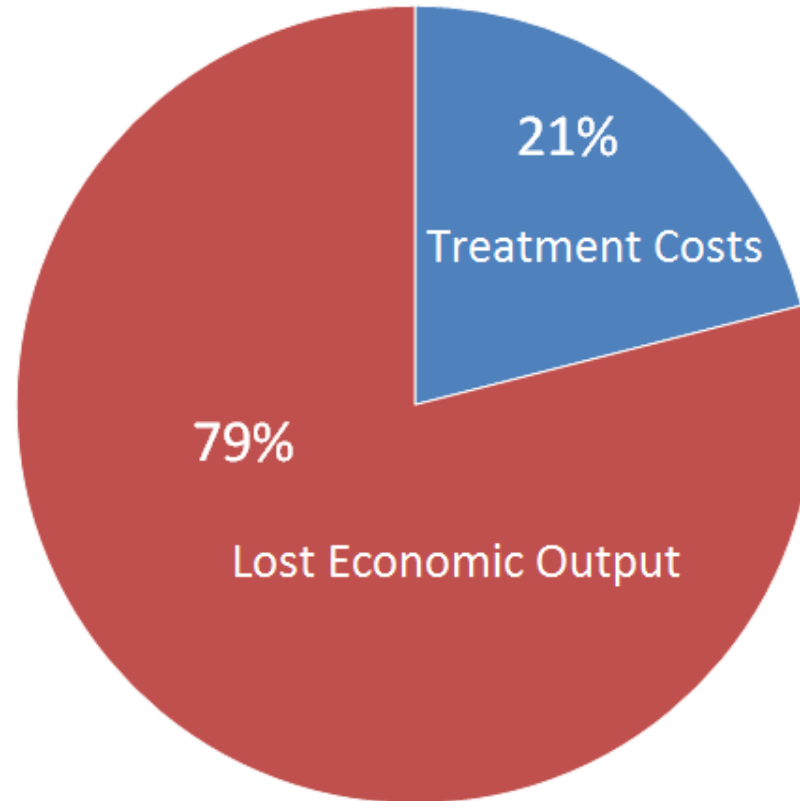


25% of Those With Chronic Illness Also Have Activity Limitations



Costs are double for patients with a chronic illness & activity limitation.

Treatment Costs Small Compared to Productivity Losses



79% of cost of chronic illness accounts is productivity losses.

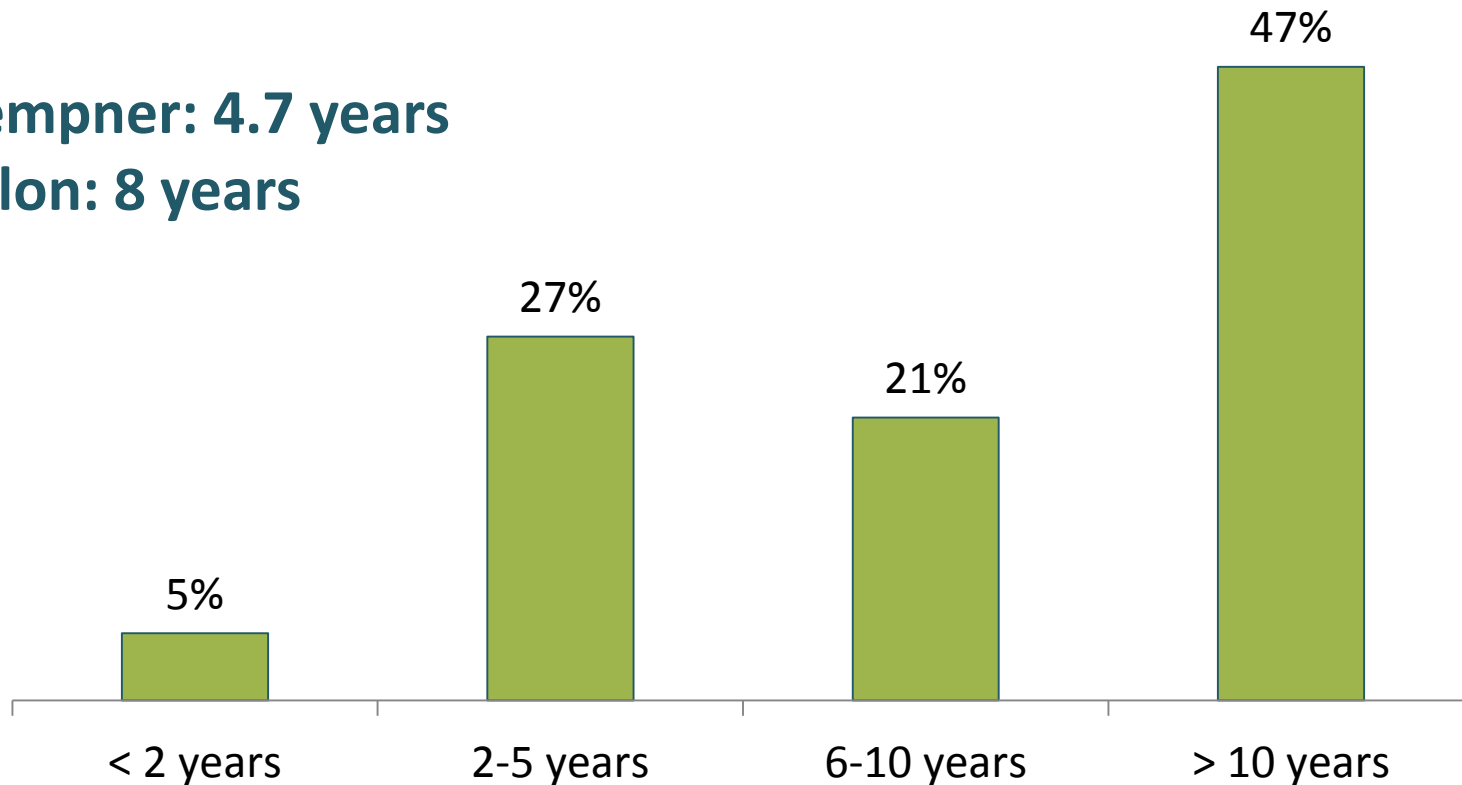
Is Lyme disease a Chronic Illness or Condition?

- **A condition is chronic if it**
 - has lasted or is expected to last twelve or more months and
 - resulted in functional limitations, including those that affect a person's ability to work or attend school.
 - and/or the need for ongoing medical care.

Duration of Illness

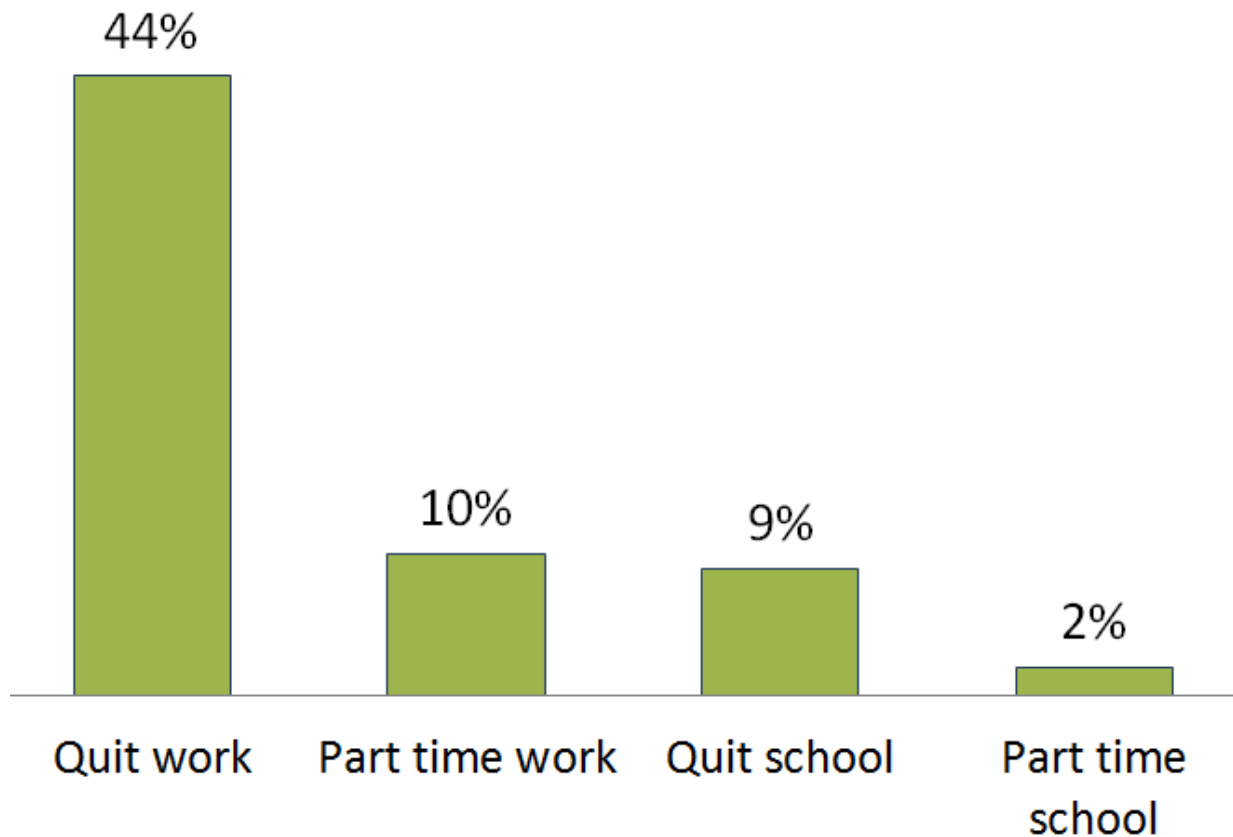
How long have you had Lyme disease?

Klempner: 4.7 years
Fallon: 8 years



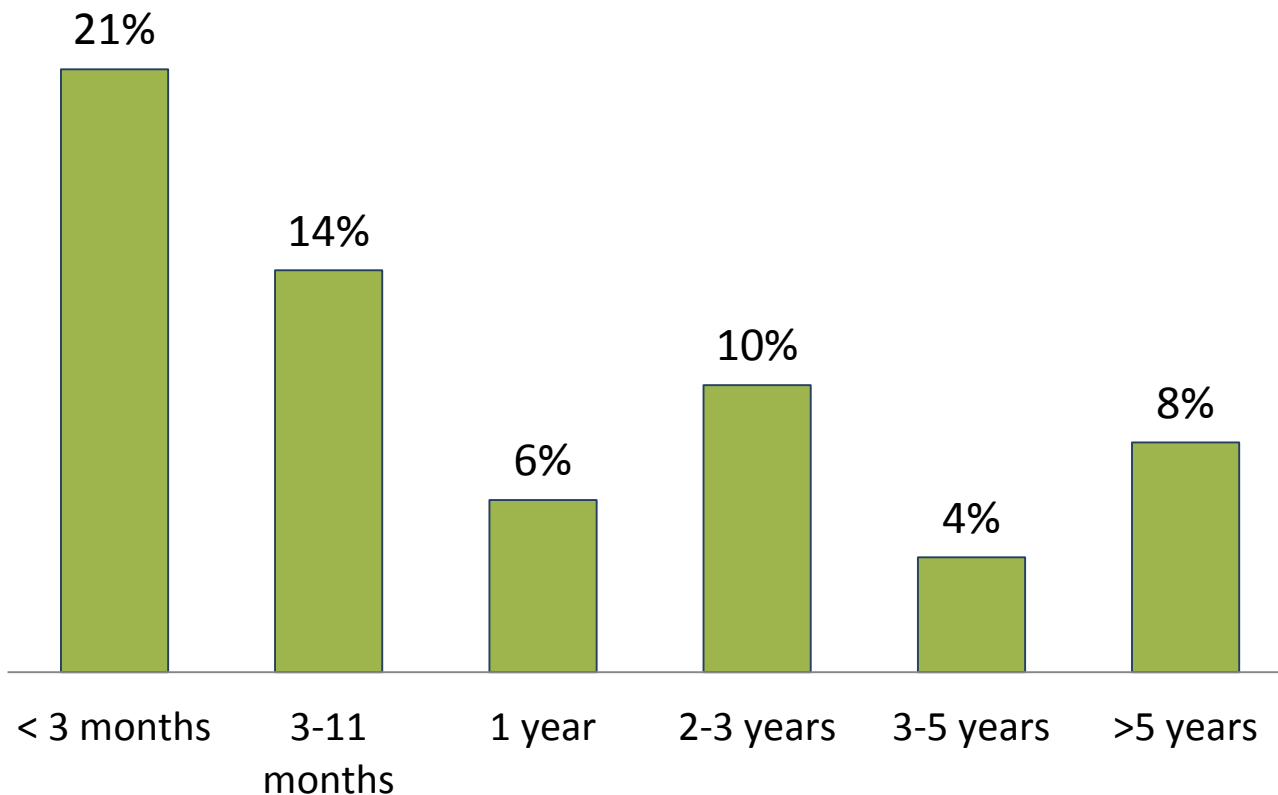
95% have had Lyme disease for 2 or more years.

Work or School Cutbacks



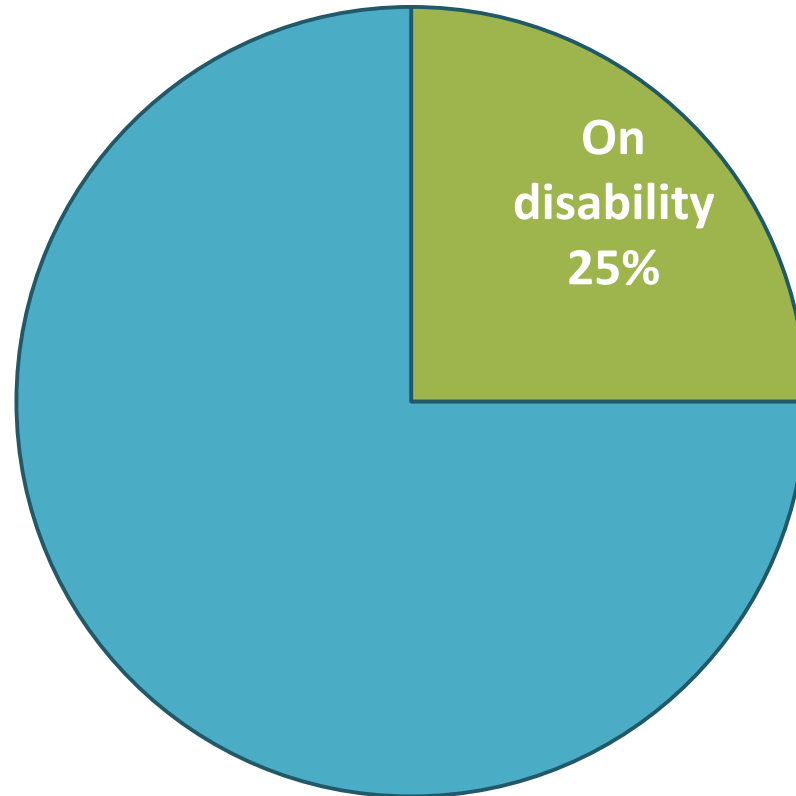
65% had to cut back or quit work or school at some point.

How Long Quit Work or School



28% were unable to work for more than a year.

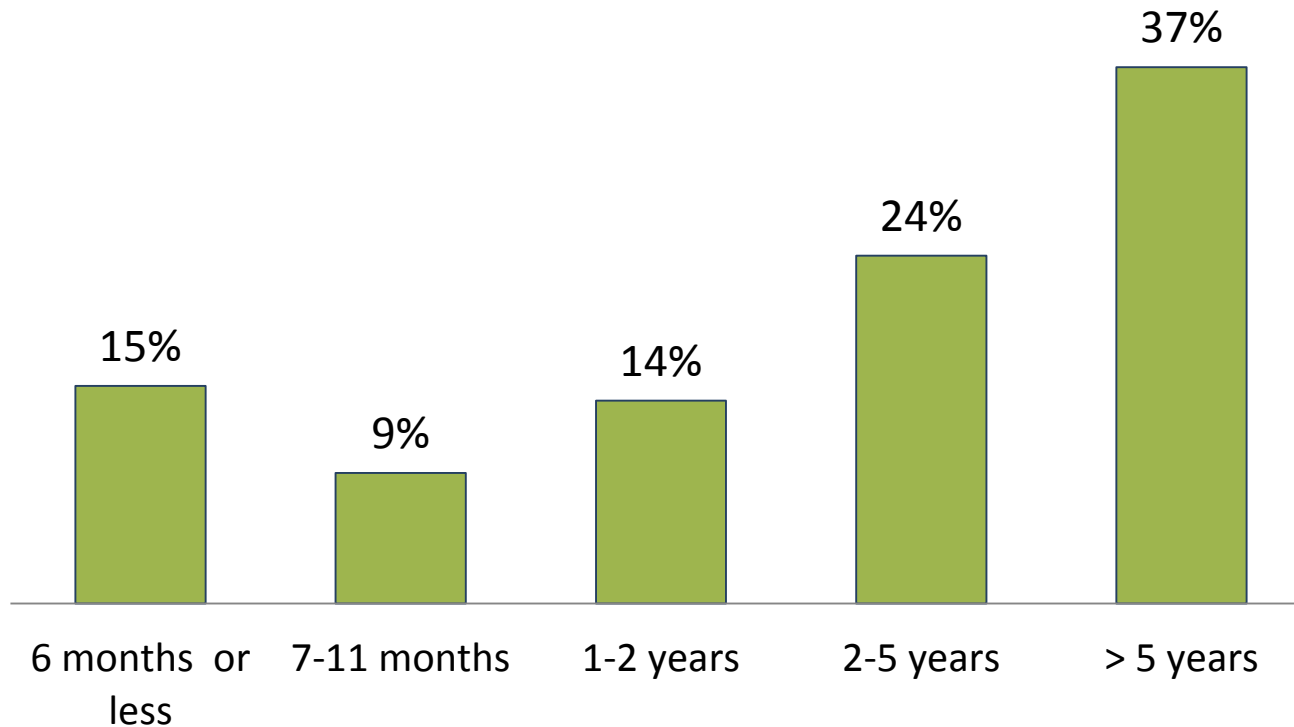
Public Support



25% of those with chronic Lyme disease have been on disability.

Duration of Disability

Length of time on public support



75% of those on disability have been for more than 1 year.

Compressing Morbidity

- Primary Prevention: Don't get the disease at all
- Secondary Prevention: Stop the disease from progressing to a serious illness
- Tertiary Prevention: Reduce Morbidity



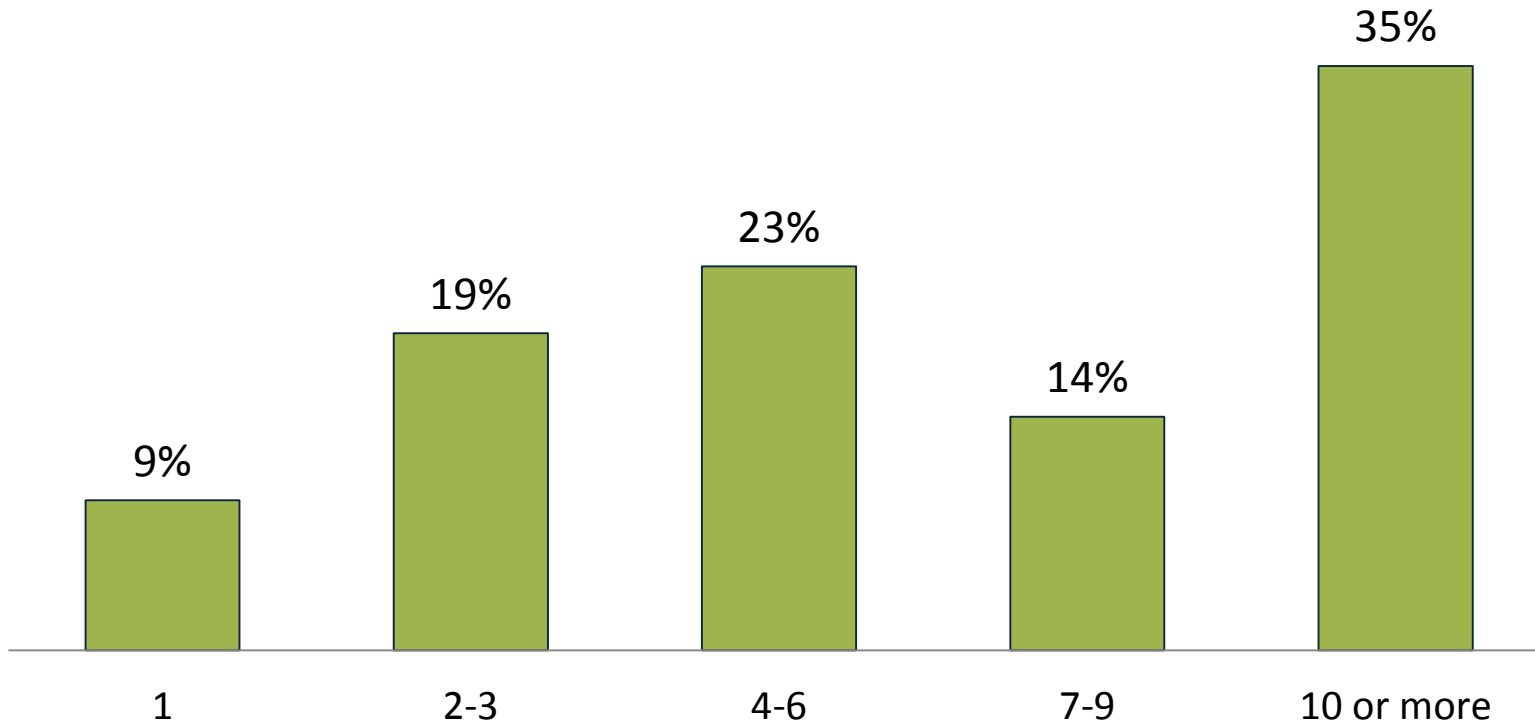
Compressing Morbidity in Lyme disease

- Primary Prevention: Awareness
- Secondary Prevention (Goal Prevention of Chronic Lyme):
 - Early diagnosis and aggressive treatment
- Tertiary Prevention of those with Chronic Lyme:
 - Treat the treatable
 - Restore quality of life and reduce and minimize life impacts
 - More effective treatments

We have a long, long way to go.

Too Many

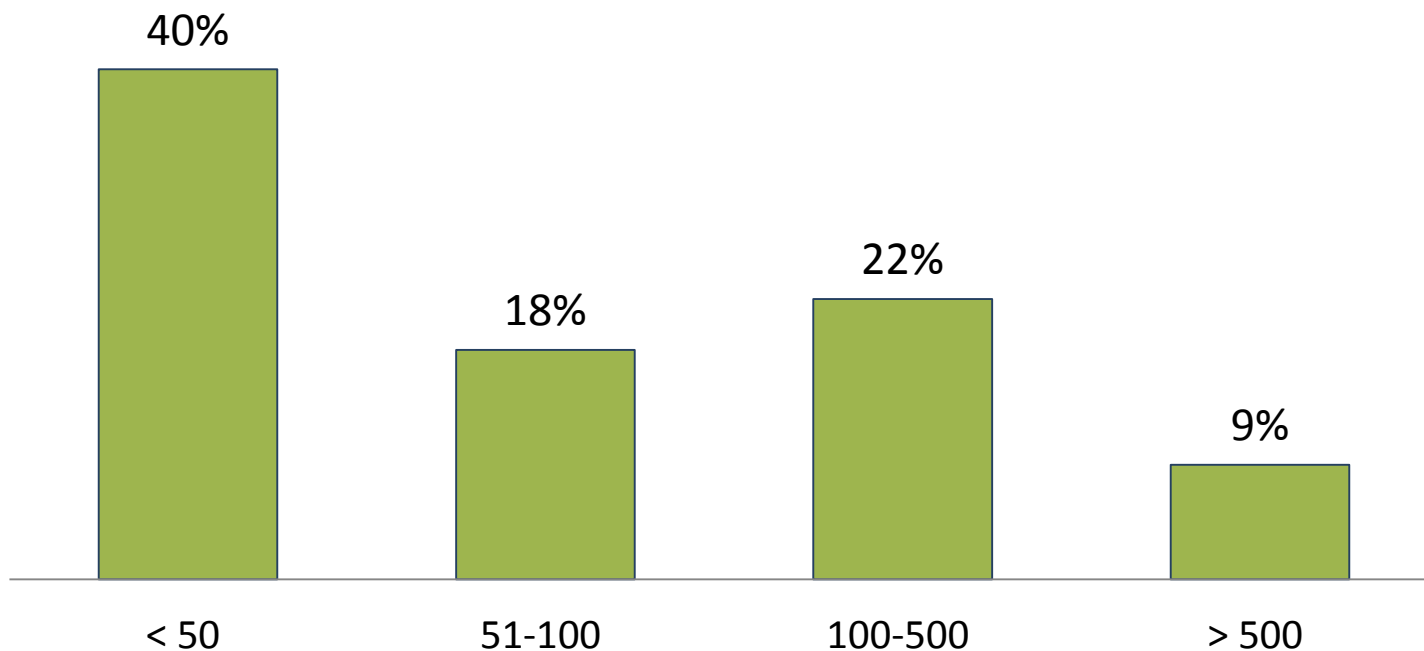
Number of Physicians to Diagnosis



50% see 7 or more physicians before diagnosis.

Too Far

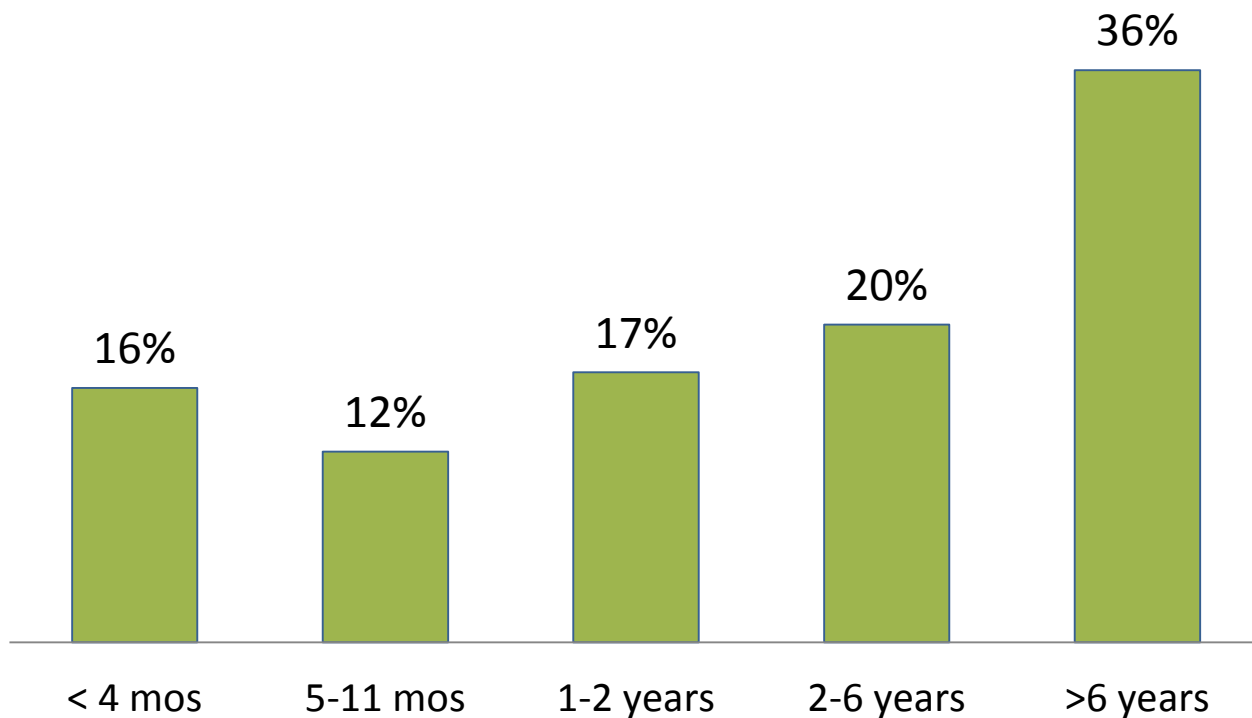
How many miles do you travel for treatment?



30% travel 100 or more miles for treatment.

Too Long

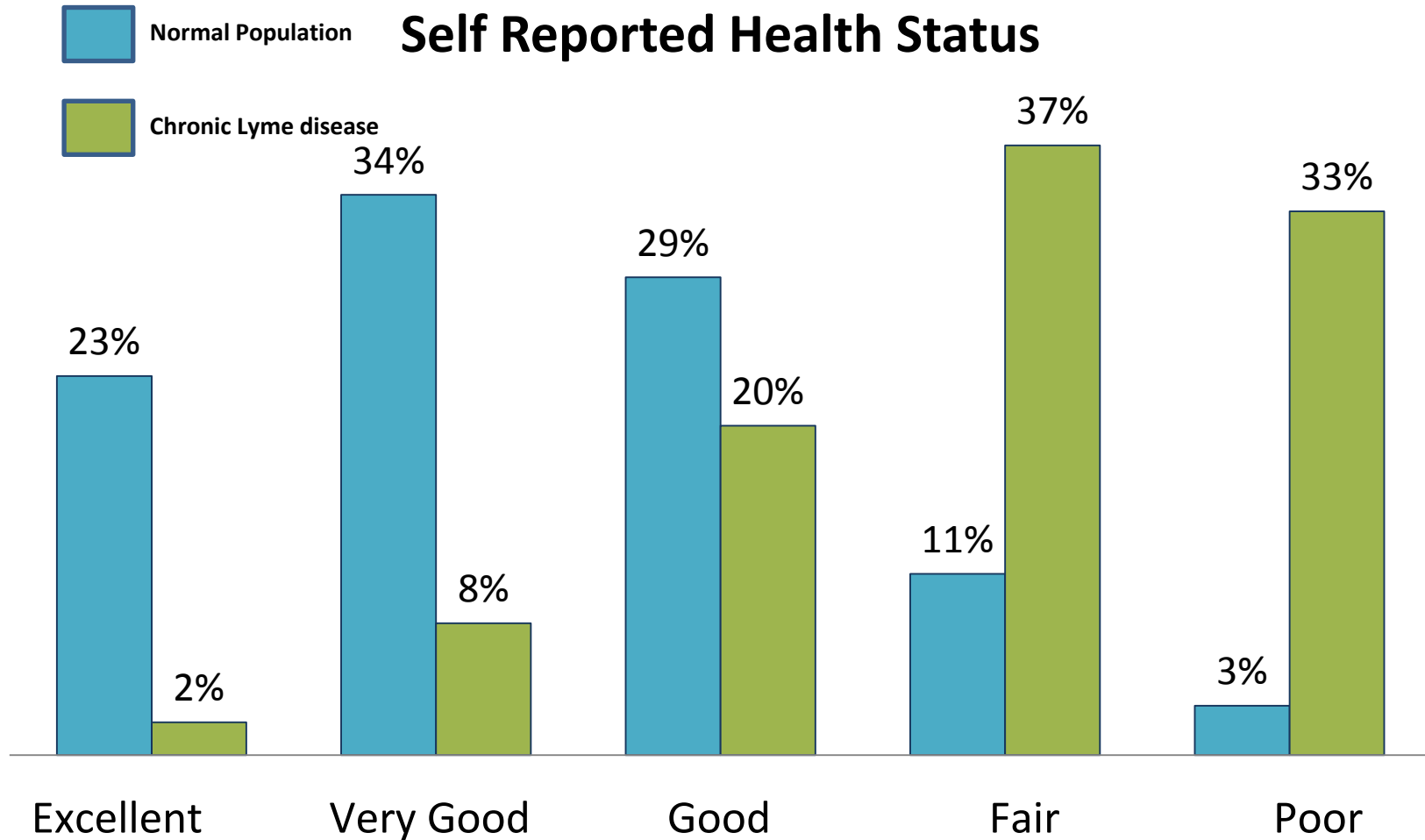
How long did it take to diagnosis?*



84% were not diagnosed within 4 months.

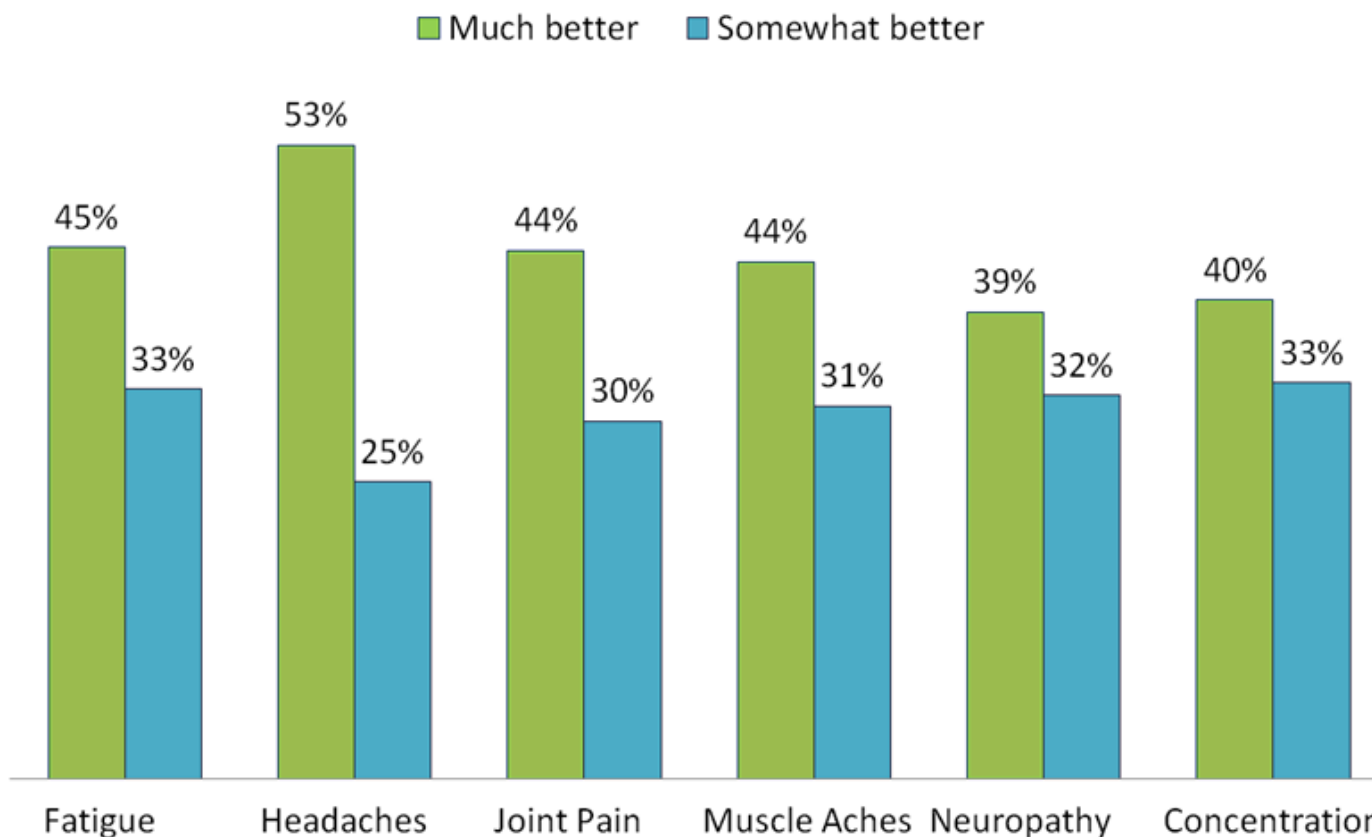
Too Sick

Klempner: Congestive
heart failure



Improvement with Treatment

If 30 days treatment was insufficient for you and you required retreatment, how has the additional antibiotic treatment affected your health





Conclusion

- Crisis of compassion
 - “No one disputes that these patients are suffering,” but adopt a “do nothing” strategy
- Fiscal irresponsibility
 - “Beyond the suffering, it's a budget-busting disease for Medicare, Medicaid and families” (Alzheimer’s)
- Ignoring consequences is not an effective strategy
 - Abandon failed policy of minimal intervention
 - Adopt policy of aggressive intervention



Lymedisease.org



Lorraine Johnson, JD, MBA