

# Quality of Life in Patients with Lyme Disease Chartbook

Conducted 2013



A **lymedisease.org** Survey

# 5992

## Total Responses

Date Created: February 12, 2013

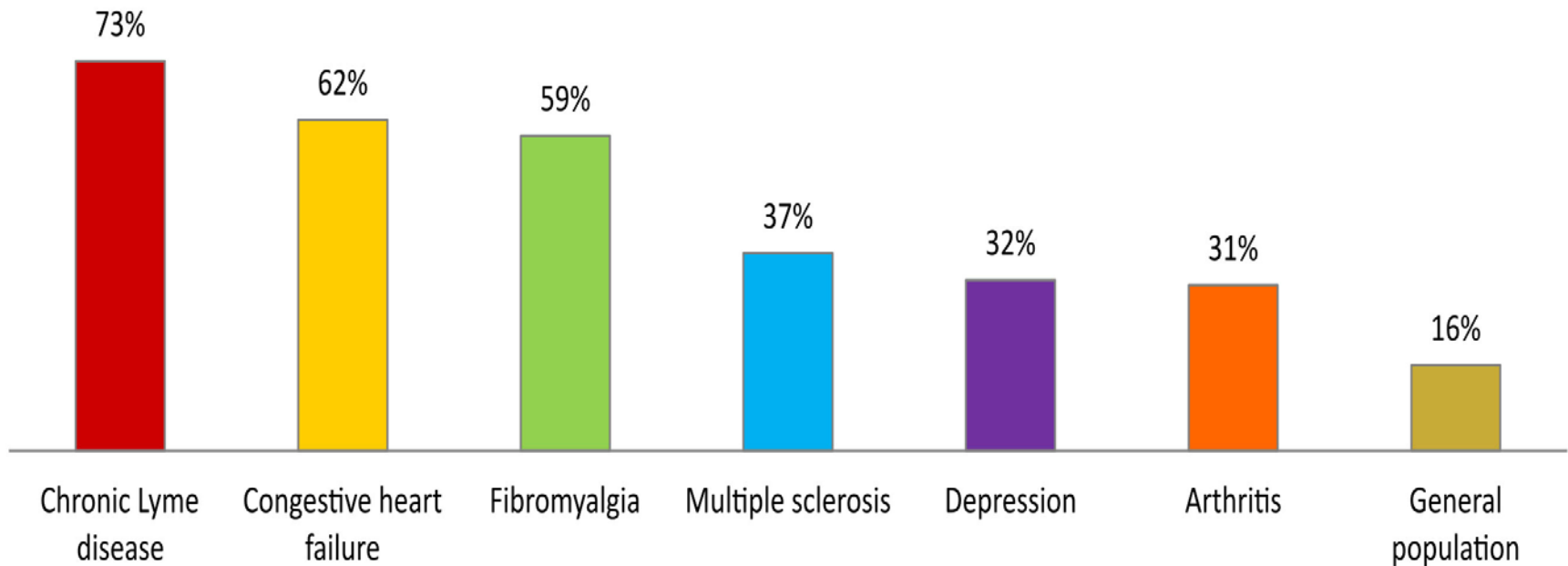
This survey was conducted by LymeDisease.org over the internet during the course of a year beginning in February 2013. It is published in a peer reviewed journal, which is available open access. (For citation, see notes.) The purpose of this study was to document the severity of chronic Lyme disease (CLD) compared to other chronic conditions using the Health Related Quality of Life HRQoL metric developed by the Centers for Diseases Control. The study also examined healthcare utilization rates and employment and productivity losses in patients with CLD.

**Conclusions.** CLD patients have significantly impaired HRQoL and greater healthcare utilization compared to the general population and patients with other chronic diseases. The heavy burden of illness associated with CLD highlights the need for earlier diagnosis and innovative treatment approaches that may reduce the burden of illness and concomitant costs posed by this illness.

The CDC HRQOL self-assessed health status measures how individual perceive their health, which is rated as excellent, good, fair or poor. CLD patients perceived themselves as significantly more ill than those with other chronic conditions.

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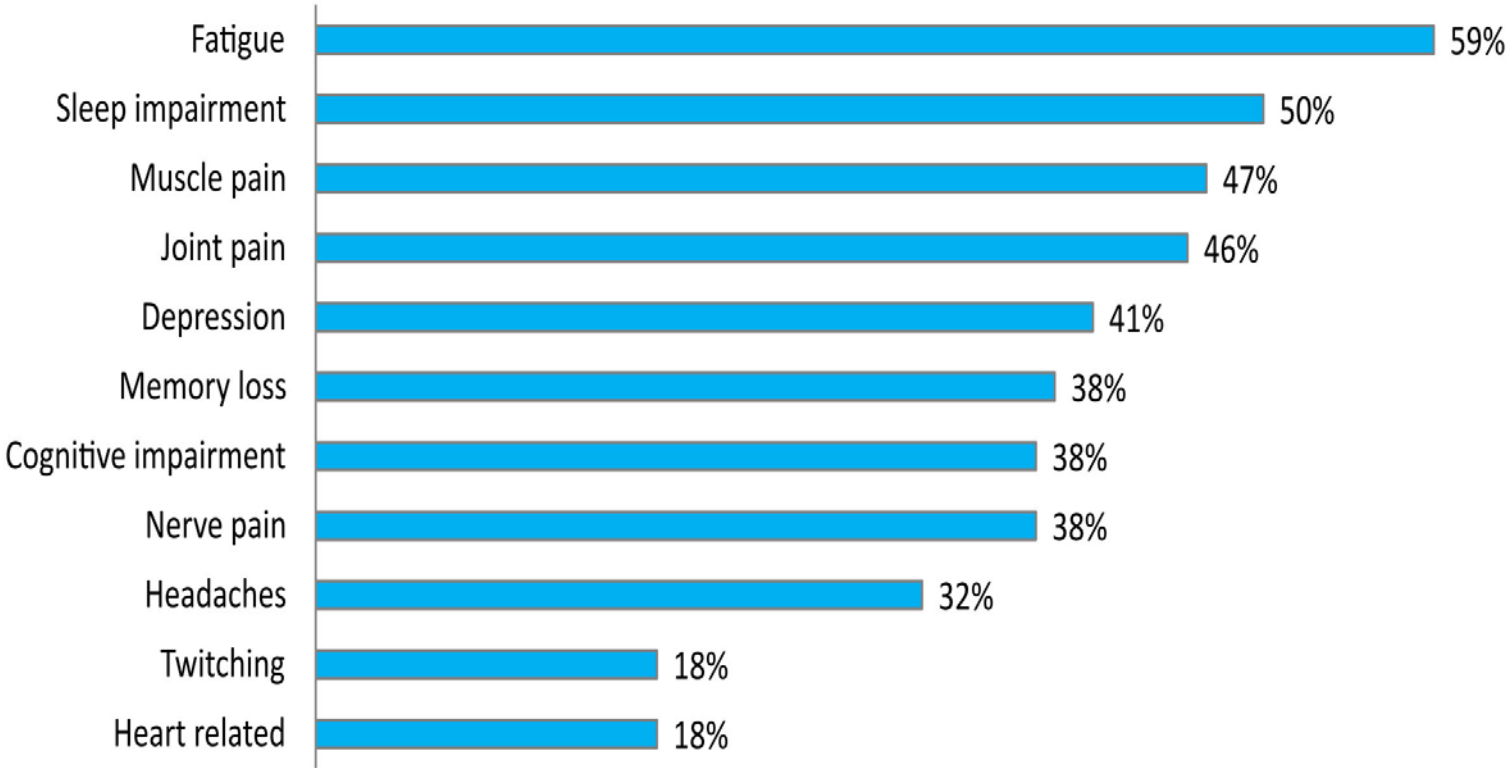
### More CLD patients report fair or poor quality of life than other diseases



**Chronic Lyme patients reported an average of 3 severe or very severe symptoms, with 13% reporting at least one symptom and 63% reporting two or more symptoms as severe or very severe.**

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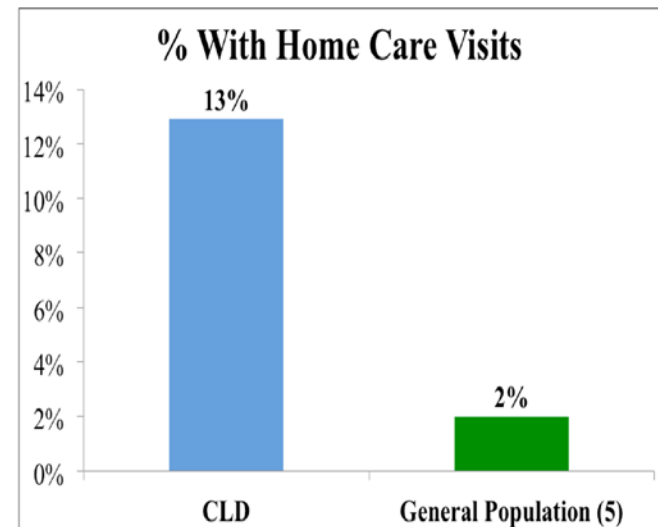
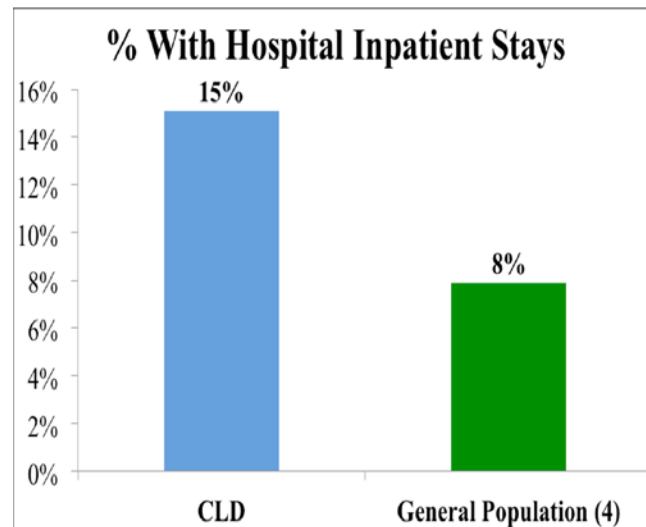
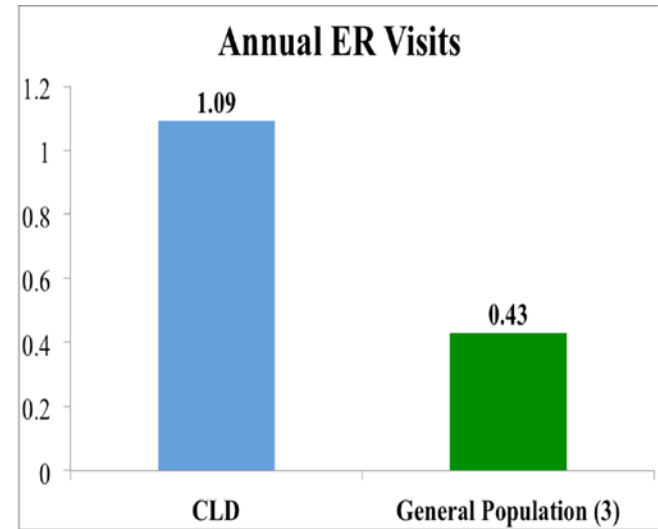
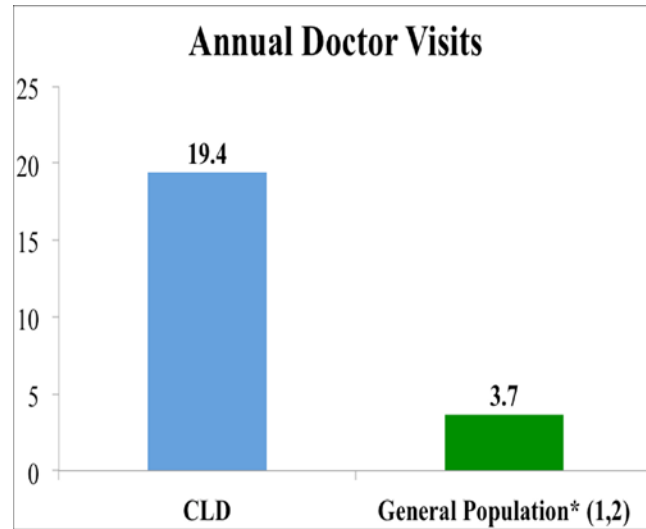
**Participants who rated Lyme symptoms as severe or very severe**



## CLD patients report high healthcare utilization levels compared to the general population.

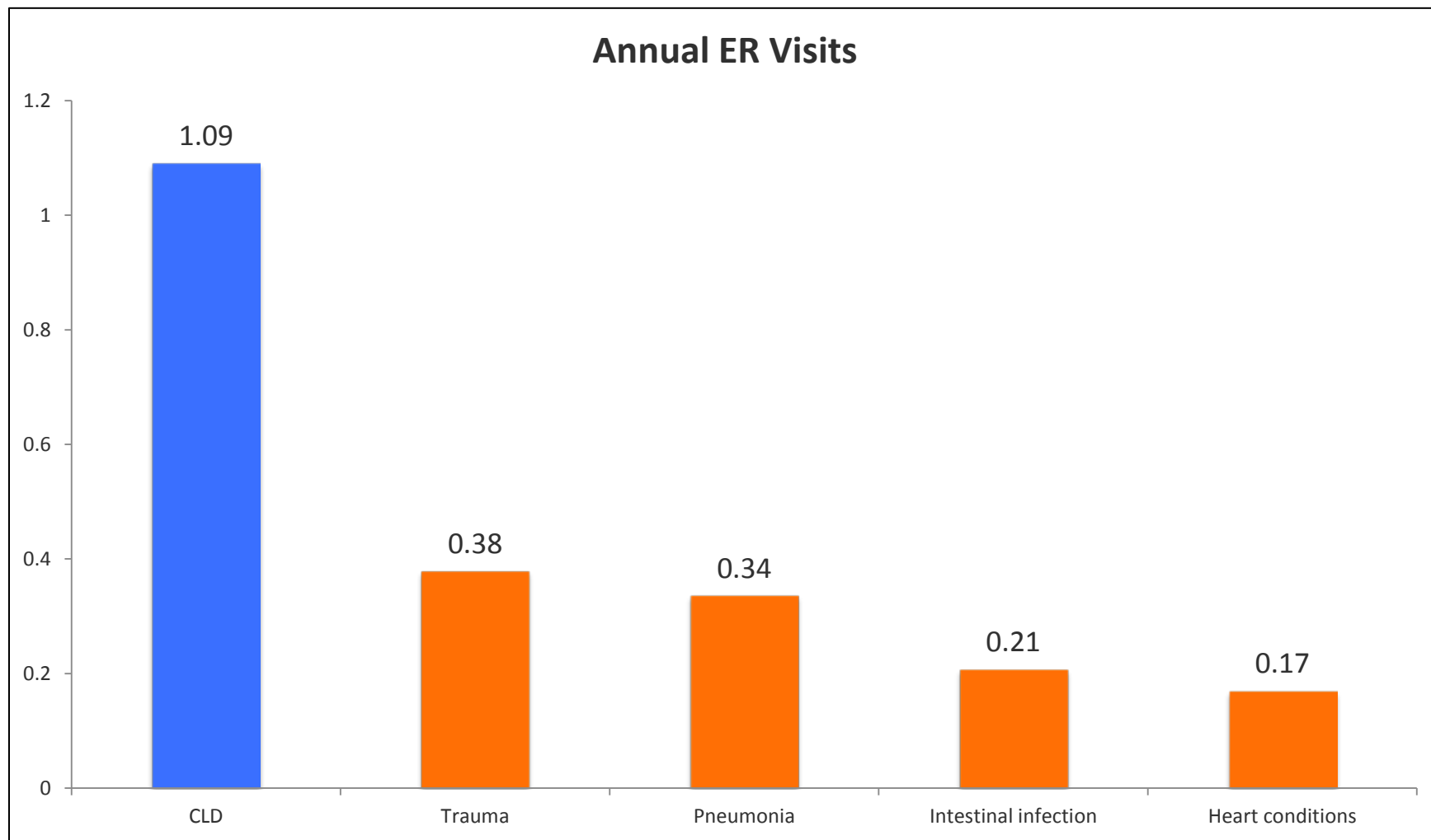
Compared with the general population, CLD patients visited healthcare providers 5 times more often and emergency departments more than twice as often.

They were almost twice as likely to stay overnight in a hospital and were roughly six times more likely to receive or pay for homecare visits.

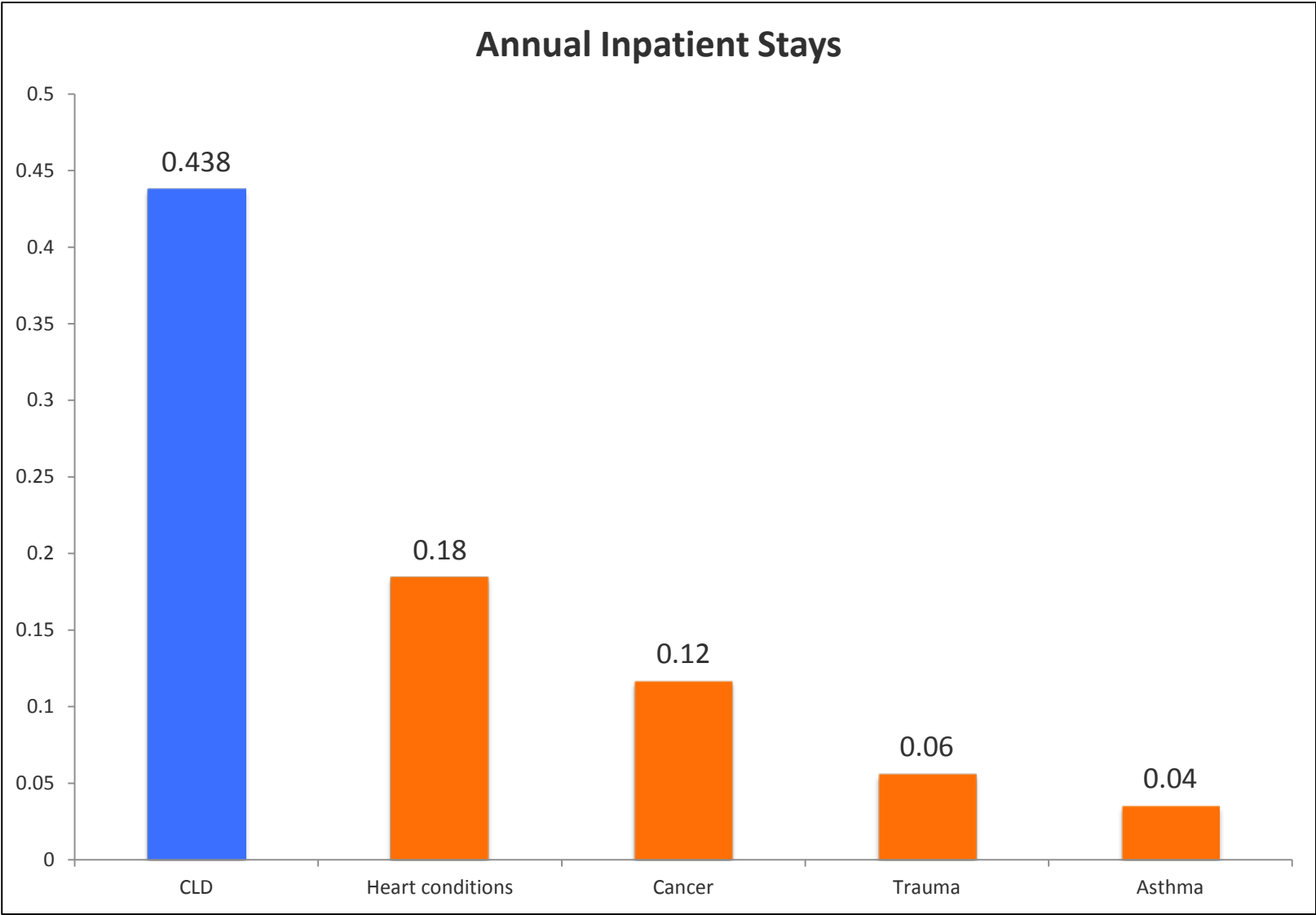


**CLD patients have more emergency room visits than other high utilization conditions.**

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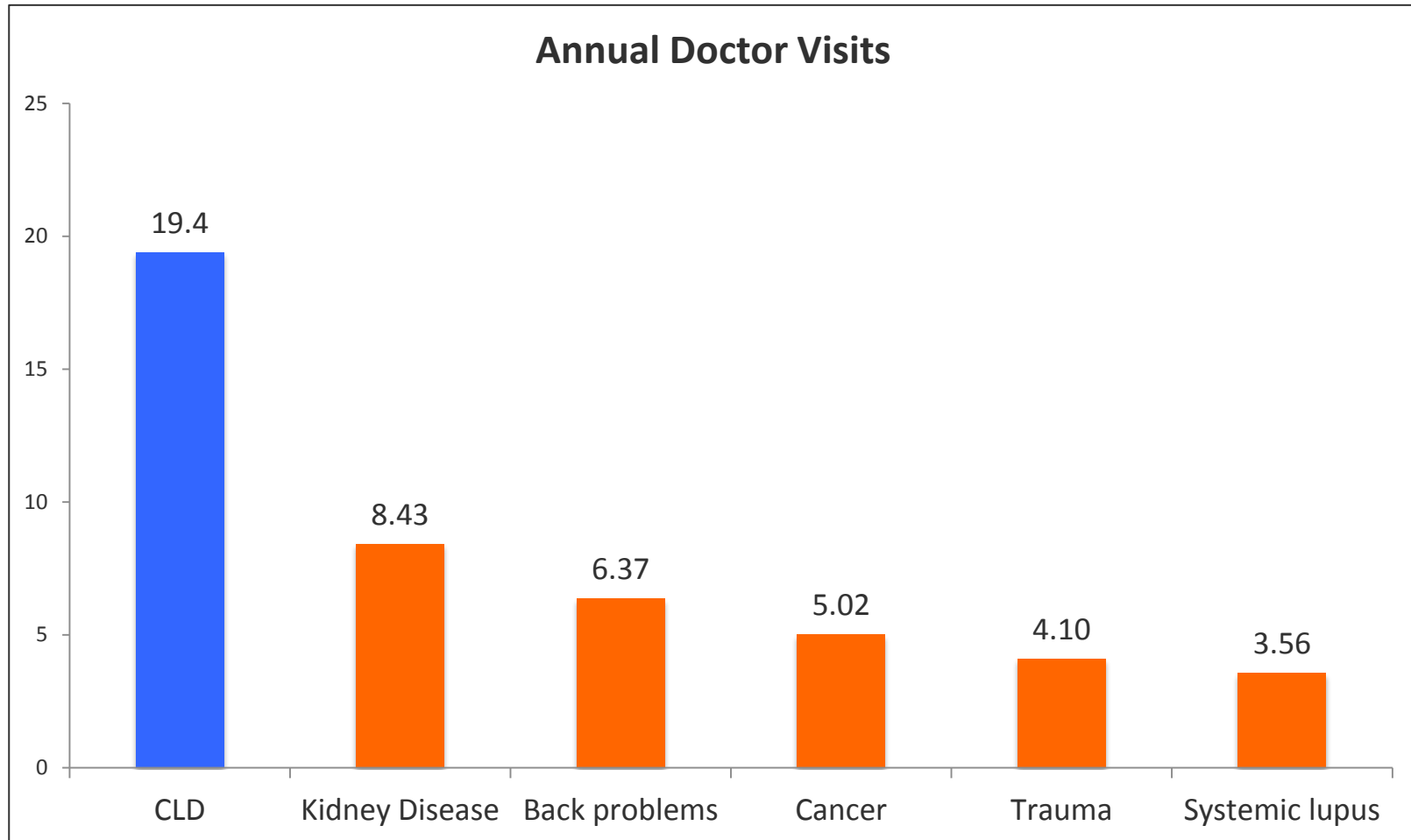


**CLD patients have more overnight stays in the hospital than other high utilization conditions.**



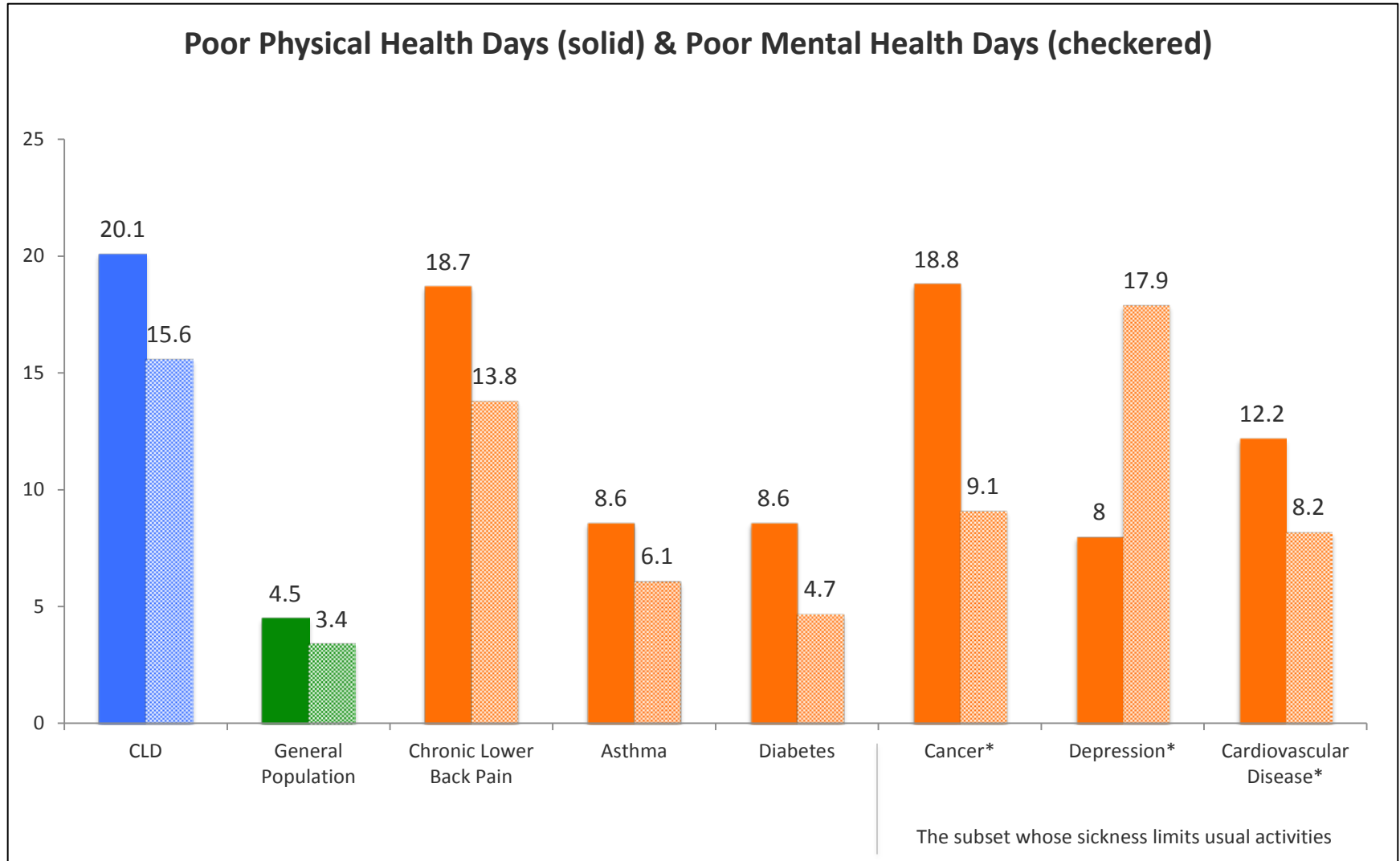
**CLD patients have more visits to healthcare providers than other high utilization conditions.**

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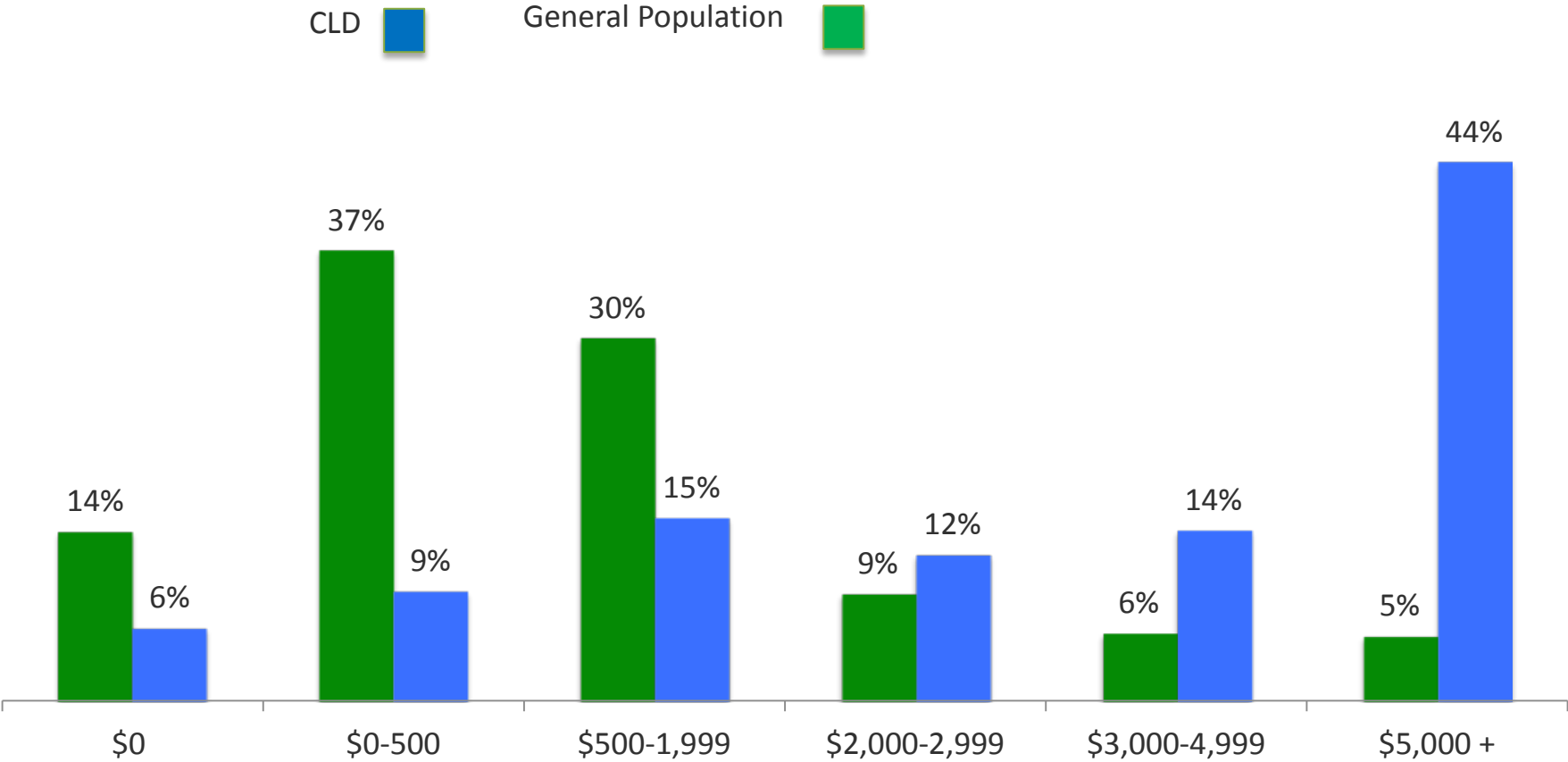


**Patients with CLD have more physical (20 days) and mental (16%) unhealthy days in a 30 day period compared to only 5 and 3 days in the general population. These unhealthy days exceed those of other serious diseases including chronic back pain, asthma, diabetes, and cancer.**



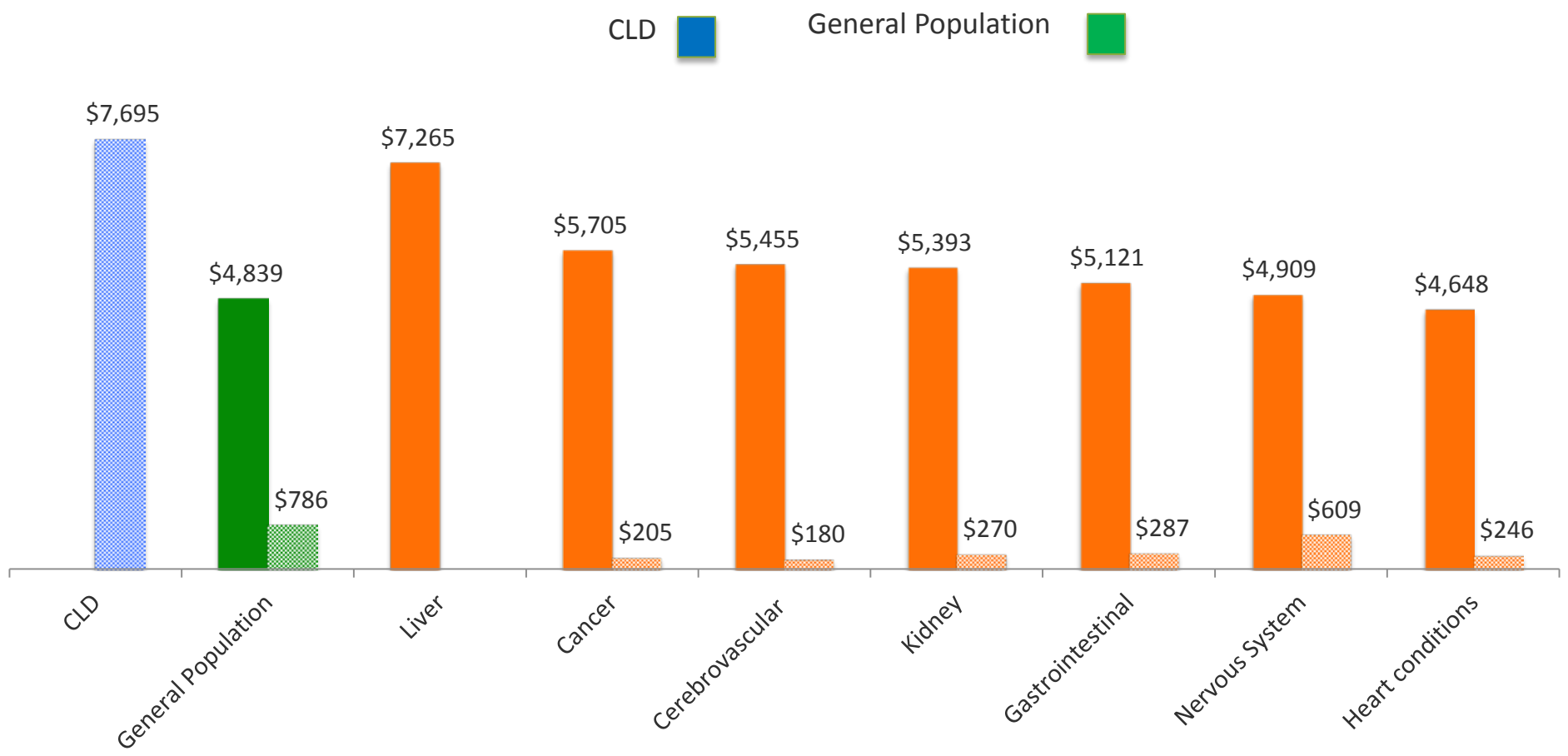
# Annual out-of-pocket healthcare costs high compared to general population.

Out of pocket costs for patients with chronic Lyme disease are much higher than those for the general population. 44% report out-of-pocket costs exceeding \$5,000 per year, compared with only 5% of the general population.



# Out-of-pocket costs for healthcare greatly exceed those of other diseases.

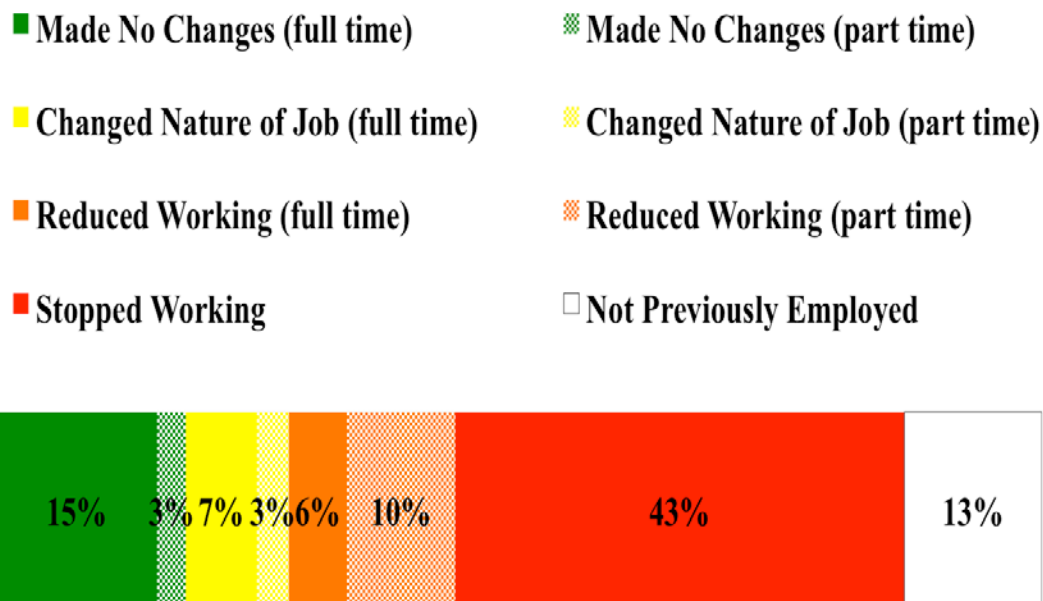
Annual Total (solid) & Out-of-Pocket (checkered) Health Care Costs for CLD and Top 7 Most Expensive Conditions.



## CLD patients have significant impairment in work productivity. 42% have quit work and 25% have cut back or changed the nature of their work.

Approximately 42% stopped working as a result of Lyme disease (with 24% reporting that they received disability as a result of CLD), while 25% reported having to reduce their work hours or change the nature of their work due to Lyme disease. These figures compare with 6% of the USA population that is unable to work due to health problems and 3% that are limited in work due to health problems .

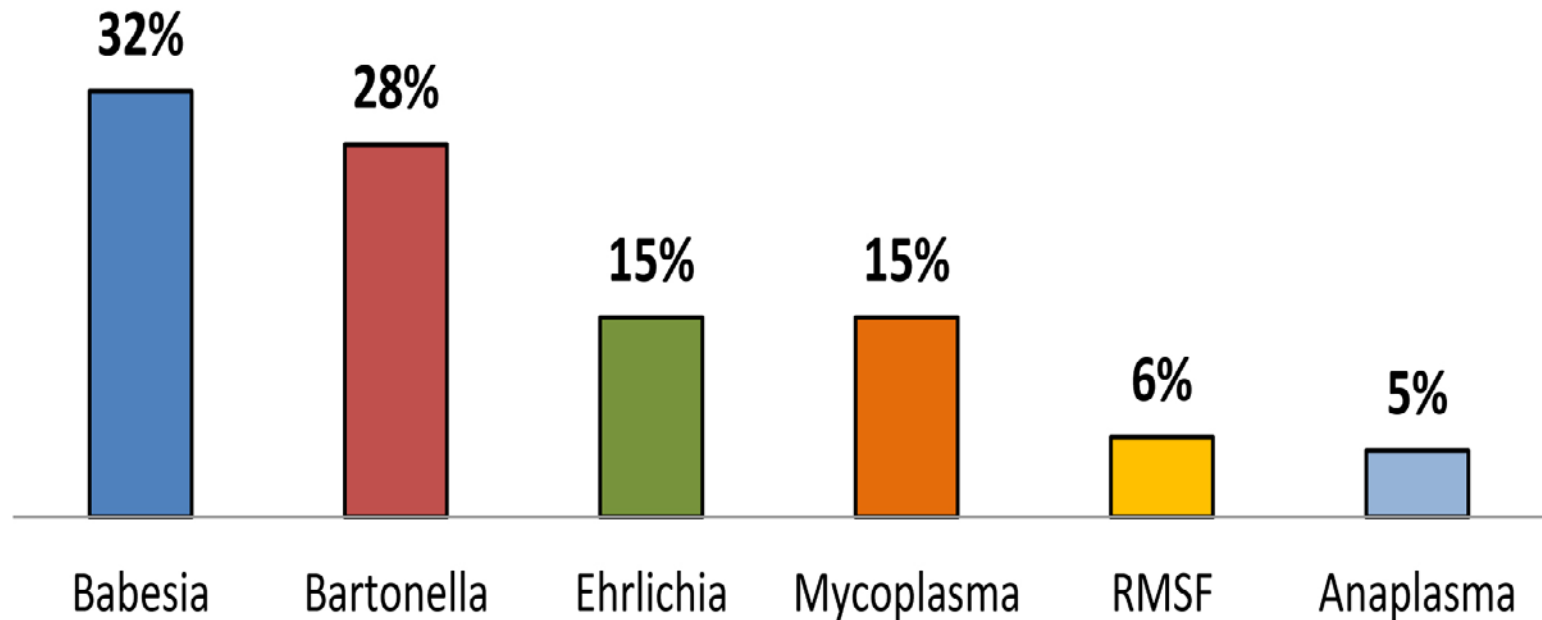
Patients able to continue working missed 15 days of work during the preceding 240-day work year, and they reported an inability to concentrate while at work (so-called presenteeism) during 42 days of work in the preceding year due to illness.



**Tickborne coinfections confirmed by serological testing were reported by 53% of patients with CLD.**

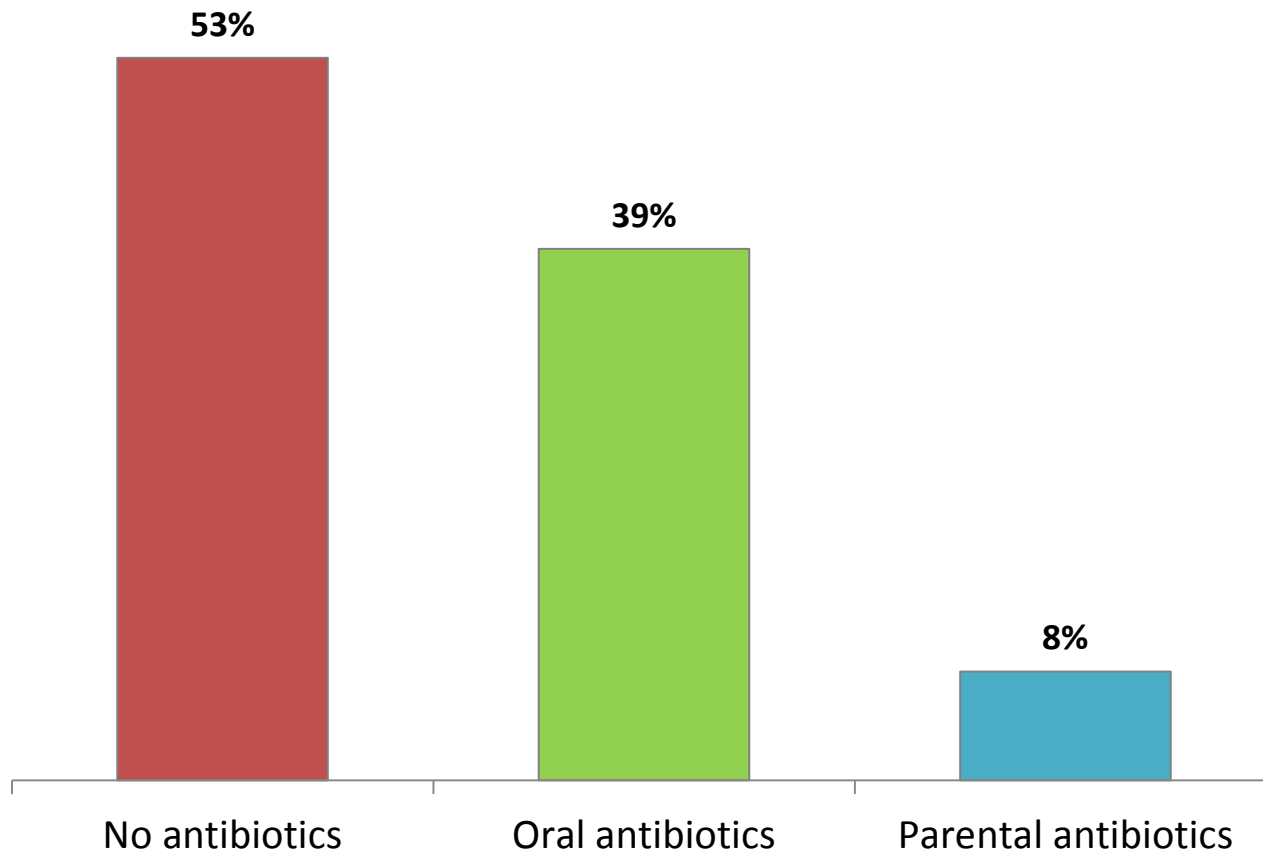
## **Coinfections**

The majority of patients with chronic Lyme disease report at least one coinfection. 30% report two or more coinfections.



**Roughly half of CLD patients are not on antibiotics. Of the 47% who are on antibiotics, 92% are only on oral antibiotics.**

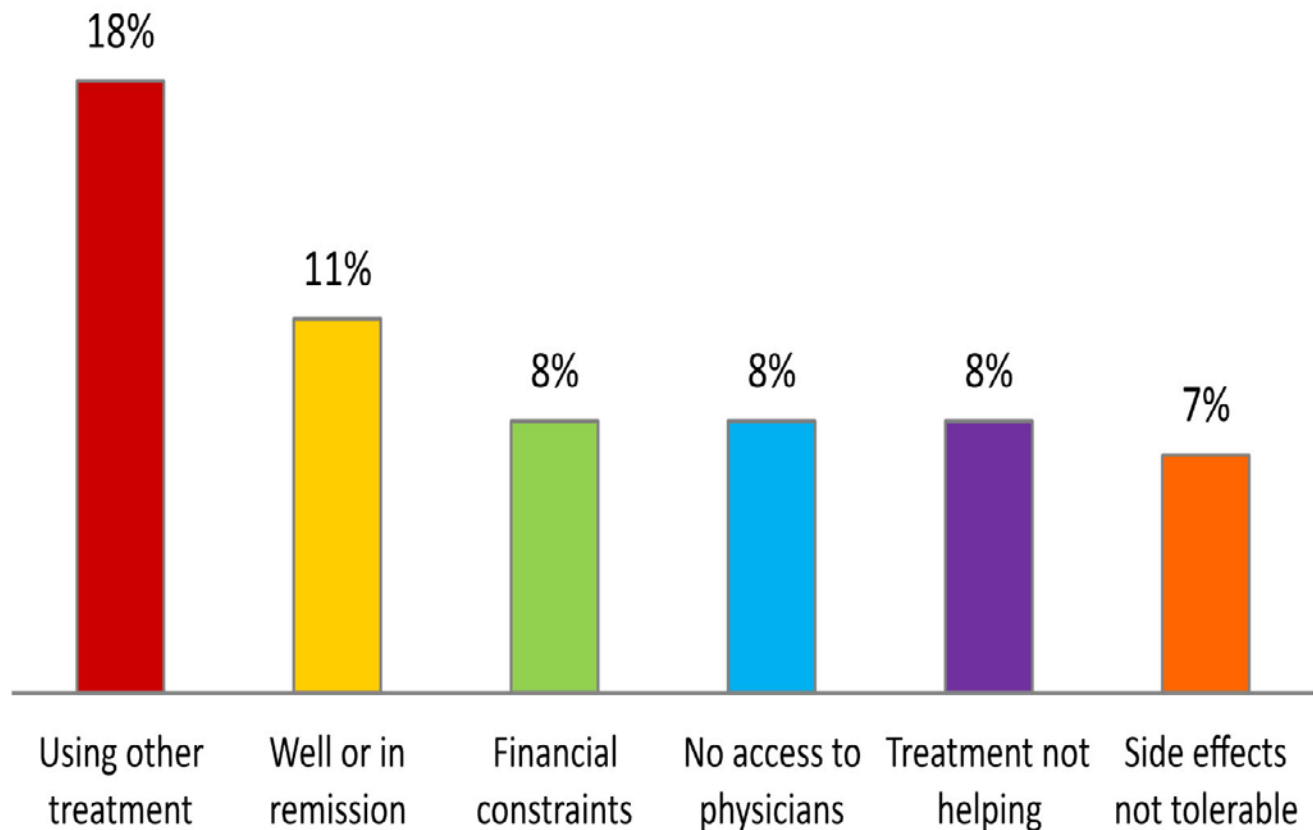
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Chronic Lyme patients who reported not taking antibiotics (53%) cited many reasons. 11% were well. 16% noted financial constraints or a lack of treating physicians. 15% indicated that medications were either not working or the side effects were not tolerable.

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## Main reason not taking antibiotics



## Notes:

This survey was conducted over the internet in the United States between February and December, 2013 and drew over 5,000 responses in that period. It was a collaboration between LymeDisease.org and Dr. Jennifer Mankoff at Carnegie Mellon University and was published in a peer review journal. (Citation below.)

The survey was answered by patients with Lyme disease in the United States who were 18 years old or older. The average age was 48.

For more than ten years, LymeDisease.org has been conducting patient surveys to bring the perspective of patients to the forefront. You can read the results of two of our peer reviewed surveys listed below or follow the results of our other surveys at LymeDisease.org. In 2015, LDo launched its big data project, MyLymeData, which is a PCORnet project.

For further information, contact the lead author, Lorraine Johnson, JD, MBA at [lbjohnson@lymedisease.org](mailto:lbjohnson@lymedisease.org).

Johnson L, Aylward A, Stricker RB. Healthcare access and burden of care for patients with Lyme disease: a large United States survey. Health Policy. 2011 Sep;102(1):64-71. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/21676482>.

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; 2. Available from: <http://dx.doi.org/10.7717/peerj.322>.



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Visit [LymeDisease.org](http://LymeDisease.org) for more  
information about our patient surveys and  
our big data project, MyLymeData.



A **lyme**disease.org Survey