



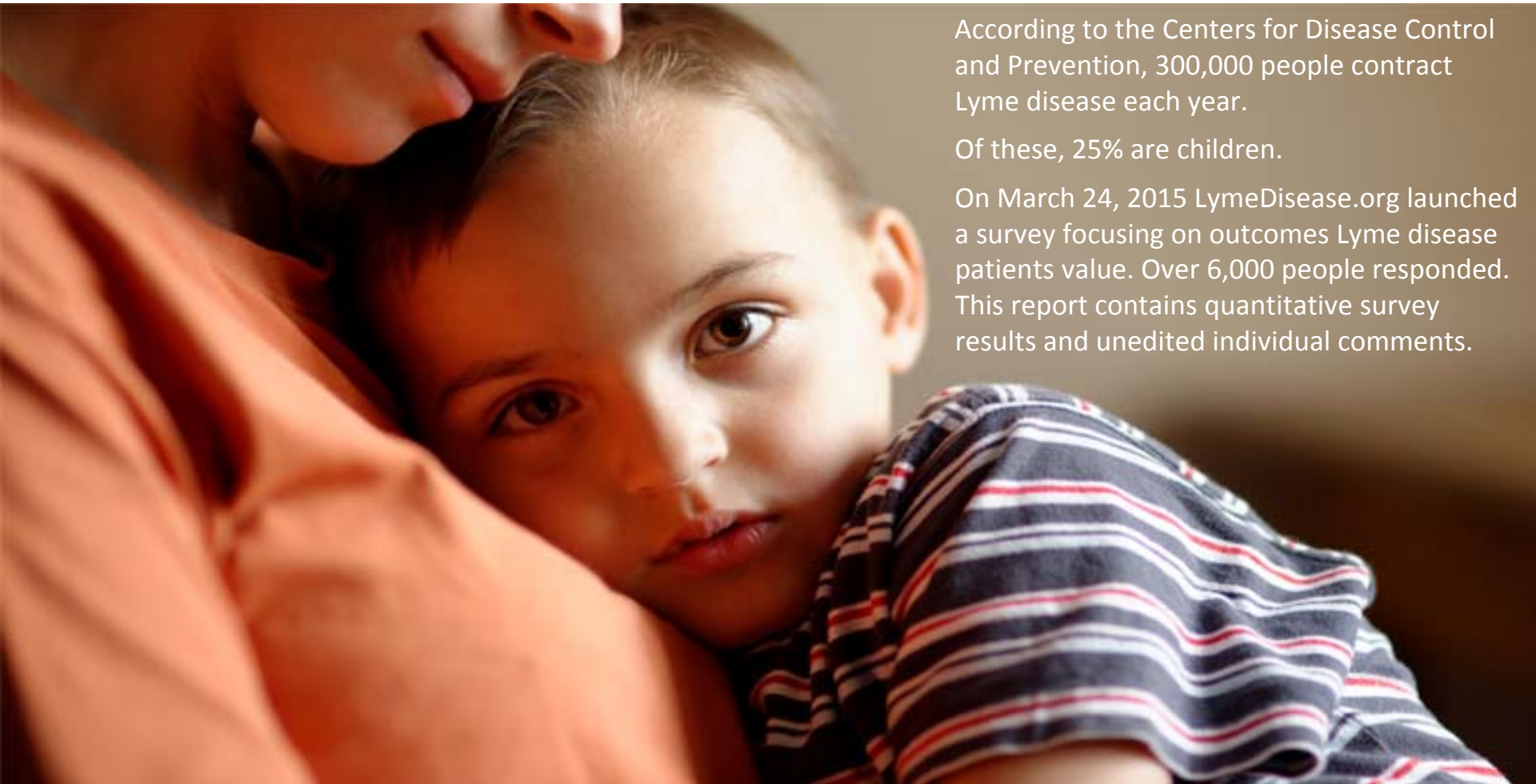
Outcomes Important to Lyme Patients

Results of a LymeDisease.org patient survey conducted in 2015



A LymeDisease.org Survey

Description of Participants



According to the Centers for Disease Control and Prevention, 300,000 people contract Lyme disease each year.

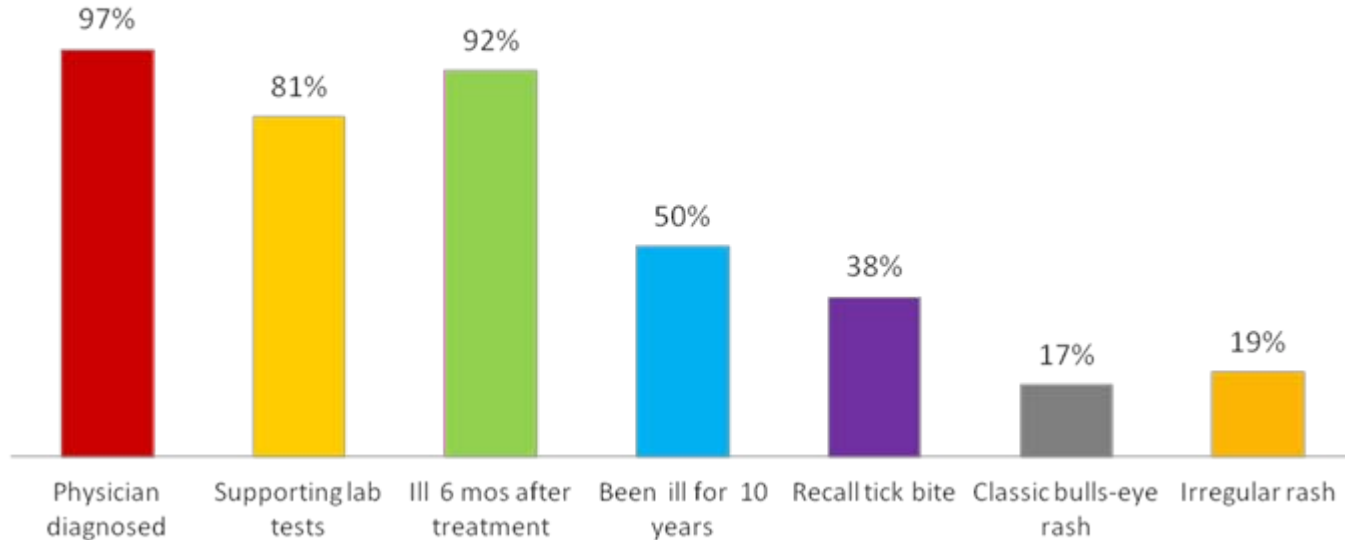
Of these, 25% are children.

On March 24, 2015 LymeDisease.org launched a survey focusing on outcomes Lyme disease patients value. Over 6,000 people responded. This report contains quantitative survey results and unedited individual comments.

Who participated in the survey?

Of the 6,104 total respondents, 97% were diagnosed with Lyme disease by a physician and 81% had supporting laboratory tests. Half had been ill for 10 years or more.

Participant characteristics

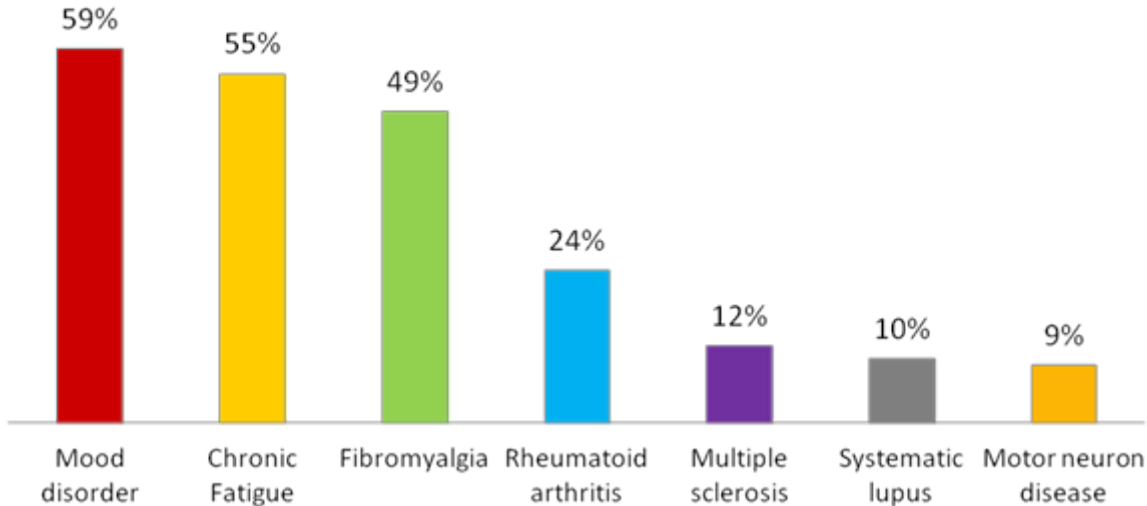


Misdiagnosis and delayed diagnosis

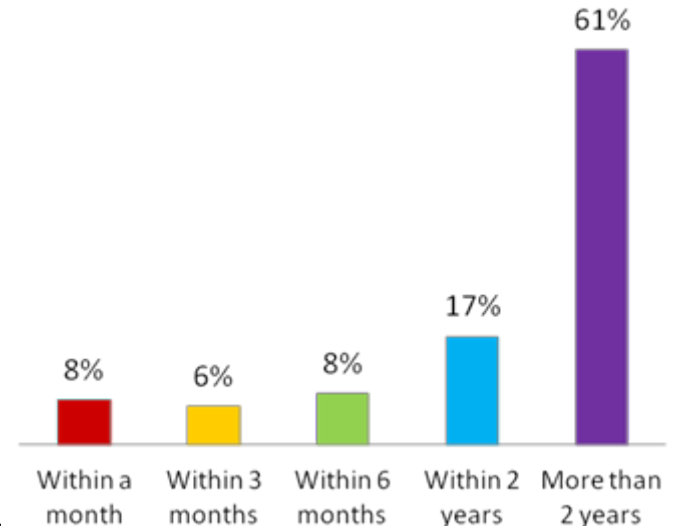
“It’s sad to see people nonfunctional from tick borne illnesses because they couldn’t get proper treatment from the onset of symptoms when disabilities could have been avoided.”

Female, 42, CT

Lyme disease previously misdiagnosed as



Time to diagnosis



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Misdiagnosis

*“**Misdiagnosis and delayed treatment stole my adolescence from me!** Delayed treatment of Lyme and co-infections have done damage that I still haven't overcome.”*

Male, 19, MA

*“After 12 doctors and countless MRIs, CAT scans and other test it was finally determined that I have Lyme. **This is a nightmare of unimaginable proportions.** I hope that this questionnaire can help.”*

Male, 59, CA

*“I was diagnosed with Lyme disease 11 years after the bite. **I was misdiagnosed with severe fatigue syndrome, IBM, IBS, MS, Lupus, Bipolar.**”*

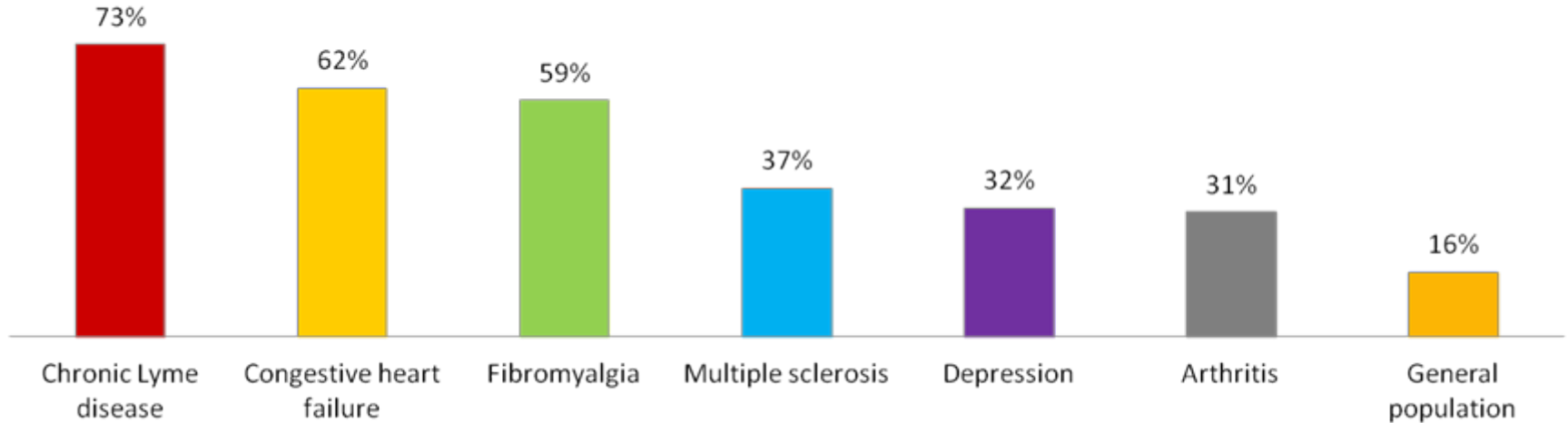
Female, 49, CA



Comparison of general health status

- 73% of participants reported their health related quality of life status as fair or poor.
- Over 70% rated improvement in quality of life and functional impairment as extremely important.

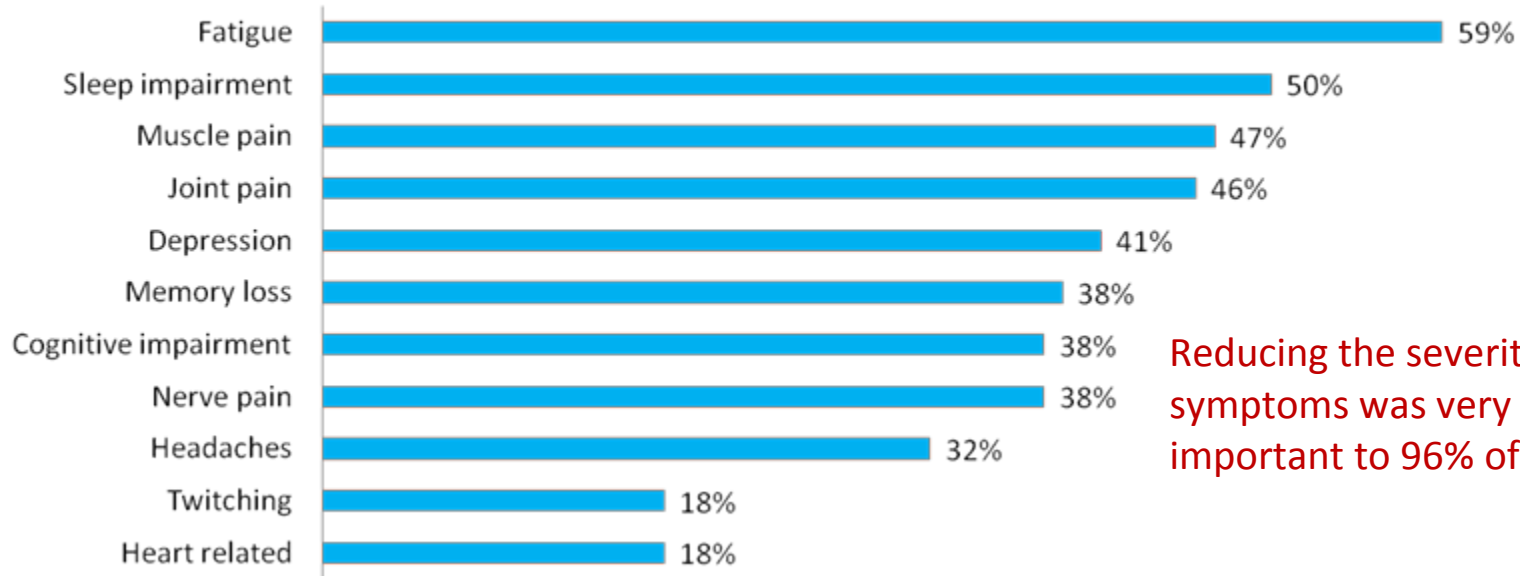
More CLD patients report fair or poor quality of life than other diseases



Symptom severity

Most participants (97%) report persisting symptoms of Lyme disease. The severity of these symptoms vary. Sixty percent of participants rate their symptoms as severe or very severe.

Participants who rated Lyme symptoms as severe or very severe



Reducing the severity of symptoms was very or critically important to 96% of participants.

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Quality Of Life

*“I was at the top of my game at my occupation of 36 years. I rode and raced, and typically came in the top five of endurance athletes in mountain bike 12 and 24 hour races. I **don't race, barely ride—sometimes don't get out of bed.** I no longer work in my industry and I am scraping to get by. Nobody understands my problem. I have lost my personality and I certainly am not the same person I was two years ago because of Lyme disease.”*

Male, 58, CA

*“I am in Year 7 of this disease and it has been very tough. When bitten, I was training for my 3rd Triathlon. **In Year 3, I could not even walk a block to my post office. It steals your life.**”*

Female, 60, CA



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Quality Of Life



*“I went from being a happy, functioning teacher and mom of two girls. It took over two years, extreme persistence, and over twenty doctors to determine that I had Lyme disease. **Everyday I wake up with pain that limits my ability to be the type of mother that I was prior to getting ill.** This is a serious endemic that gets dismissed by doctors due to inaccurate testing and misinformation.”*

Female, 35, CA

*“I lost a 13 year career in the Fire Service over this **disease.** I've spent my whole retirement paying for treatment insurance won't cover and paying overdue bills caused by my loss of income. We've also had to move in with my parents.”*

Female, 37, CA

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Quality Of Life

“I’m a 17 year old athlete who was a very good student who cared about her school work. I never missed school, never missed a homework assignment, and tried my hardest in all of my classes. But, I have been unable to be in school for the last year and a half because of Lyme Disease and the 3 co-infections I have. It’s so unbelievably hard to have your life ripped away from you because of one tick bite that escalated into something that could have been prevented. I’ve had to sit on the sidelines and watch my peers move on with their lives, while my world stopped spinning.”

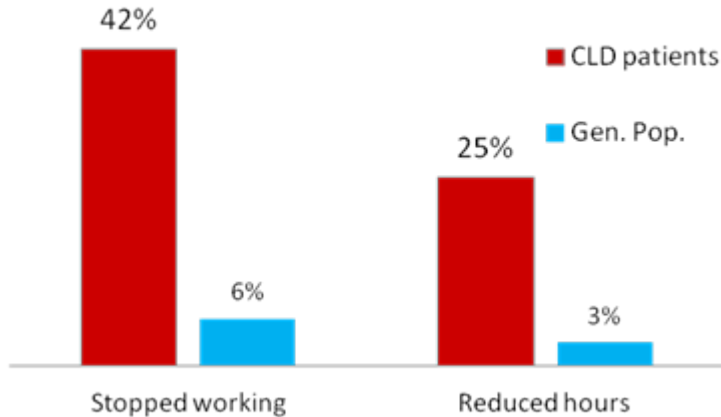
Female, 17, NJ



Financial impact

- 42% of patients with chronic Lyme disease (CLD) report either having to quit or cut back on work due to Lyme disease.*
- 17% report receiving disability currently and 20% report being on disability at some point from private insurance, or state, federal or other public agencies due to Lyme disease.

Quitting or cutting back on work



“Prior to Lyme disease I was married with an excellent career and a household income over \$200,000. This disease has cost my life, my finances, my ability to contribute to society, and I'm fighting with all I have to get well.”

Female, 35, TN

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Financial Impact



"I was a firefighter for 23 years. Lyme has changed who I am. I got Lyme from fighting forest fires. I hurt everyday but nobody wants to hear that."

Male, 40, OR

"I had to retire from my job 6 years earlier than I had planned because I could no longer concentrate, do mathematical equations, nor remember most information required for my job. I was a Mechanical Engineer."

Male, 59, FL

"This illness has taken over my life. I am unable to work to earn a decent income and rely on the kindness of others for sustainability. It has also left me in financial ruin. I simply do not comprehend the medical logic regarding this illness and patient care whatsoever."

Female, 35, NY

Key Data Points



Lab test failure rates—More than 50% false negatives

The IDSA Lyme disease guidelines recommend flawed two-tier testing. The Council of State and Territorial Epidemiologists advises the CDC on testing standards and recognizes the validity of single-tier Western blots—which are more sensitive for detecting Lyme disease.

Two-tiered testing for Lyme disease is no better than a coin toss—missing more than 50% of patients with Lyme disease.

Sensitivity and Specificity of Commercial Two-Tier Tests for Convalescent/Late Stage Lyme disease

Study/Year	Sensitivity	Specificity
Schmitz (1993)	66%	100%
Engstrom(1995)	55%	96%
Ledue (1996)	44%	100%
Tilton (1997)	45%	100%
Trevejo (1999)	29%	100%
Bacon (2003)	67%	99%
Binnicker (2008)	49%	100%
Steere (2008)	18%	99%
Average	46%	99%

Persistence in humans

The only accurate method currently available to determine persistence of Lyme bacteria is through tissue biopsies—a technique too invasive for routine clinical practice.

However, human tissue biopsies performed for other reasons demonstrate persistence after short-term treatment and are reported in the scientific literature.

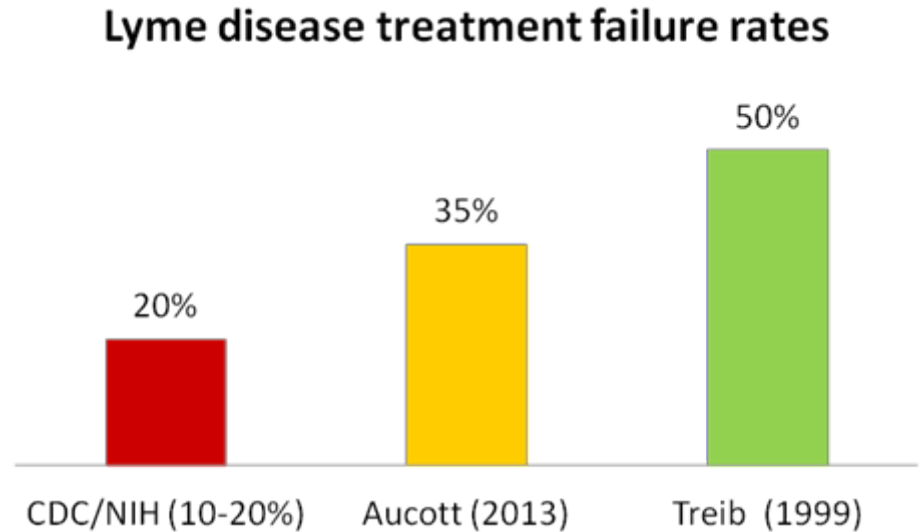
Evidence for persistent *B. burgdorferi* infection following 2-4 weeks treatment for Lyme disease in humans*

Study	Country	Persistence Shown by	Source
Weber (1988)	Europe	Histology	Brain, liver
Schmidli (1988)	Europe	Culture	Synovial fluid
Cimmino (1989)	Europe	Histology	Spleen
Preac-Mursic (1989)	Europe	Culture	Skin, CSF
Pfister (1991)	Europe	Culture	CSF
Strle (1993)	Europe	Culture	Skin
Preac-Mursic (1993)	Europe	Culture	Iris
Haupl (1993)	Europe	Culture	Ligament
Strle (1996)	Europe	Culture	Skin
Preac-Mursic (1996)	Europe	Culture	Skin, CSF
Oksi (1996)	Europe	Culture/PCR	CSF/ Brain, synovial fluid
Priem (1998)	Europe	PCR	Synovial fluid
Oksi (1999)	Europe	Culture, PCR	Blood
Breier (2001)	Europe	Culture	Skin
Hunfeld (2005)	Europe	Culture	Skin
Hudson (1998)	Australia	Culture, PCR	Skin
Steere (1988)	USA	Histology	Synovial
Kirsch (1988)	USA	Histology	Lymph node
Liegner (1993)	USA	Histology/PCR	Skin/ Blood
Battafarano (1993)	USA	Histology, PCR	Synovial fluid
Chancellor (1993)	USA	Histology	Bladder
Nocton (1994)	USA	PCR	Synovial fluid
Shadick (1994)	USA	Histology	Brain
Masters (1994)	USA	Culture	Blood
Lawrence (1995)	USA	PCR	CSF
Bayer (1996)	USA	PCR	Urine
Nocton (1996)	USA	PCR	CSF

Short term treatment failure rates are too high

Over 90% of survey respondents reported failing short term treatment protocols.

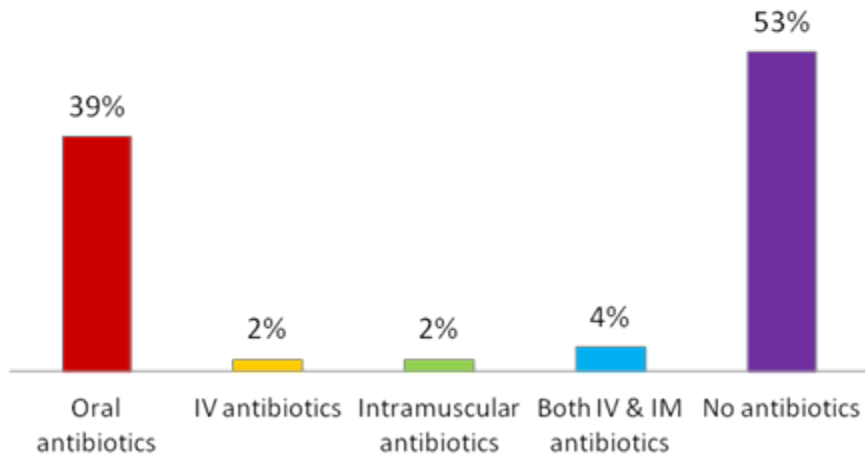
- The CDC/NIH estimates that up to 20% of Lyme patients have persisting symptoms after treatment.
- Other studies show treatment failure rates ranging from 35%-50%.



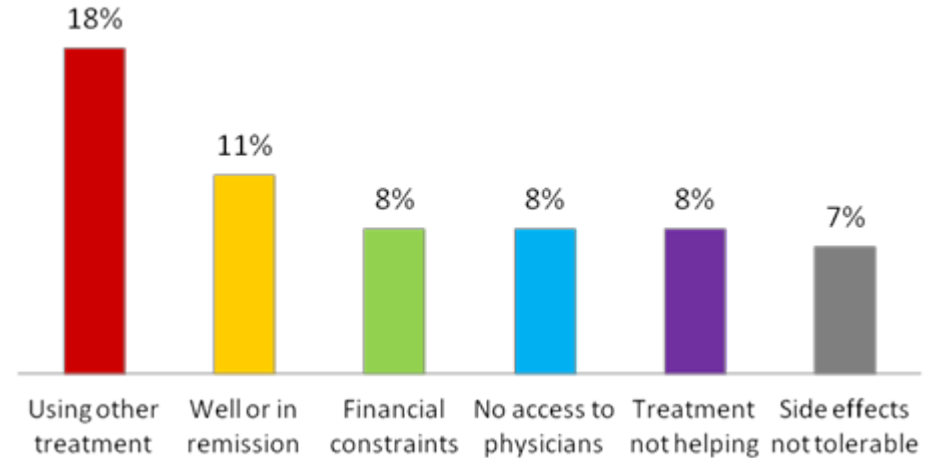
CLD patients making hard choices

- Over 50% of patients are not on antibiotics and IV antibiotic use is uncommon.
- There are many reasons patients are not on antibiotics. Some report using other forms of treatment or being well. Others are unable to afford medication or find a treating physician; for others the side effects are not tolerable or treatment is not helping.

CLD patient treatment



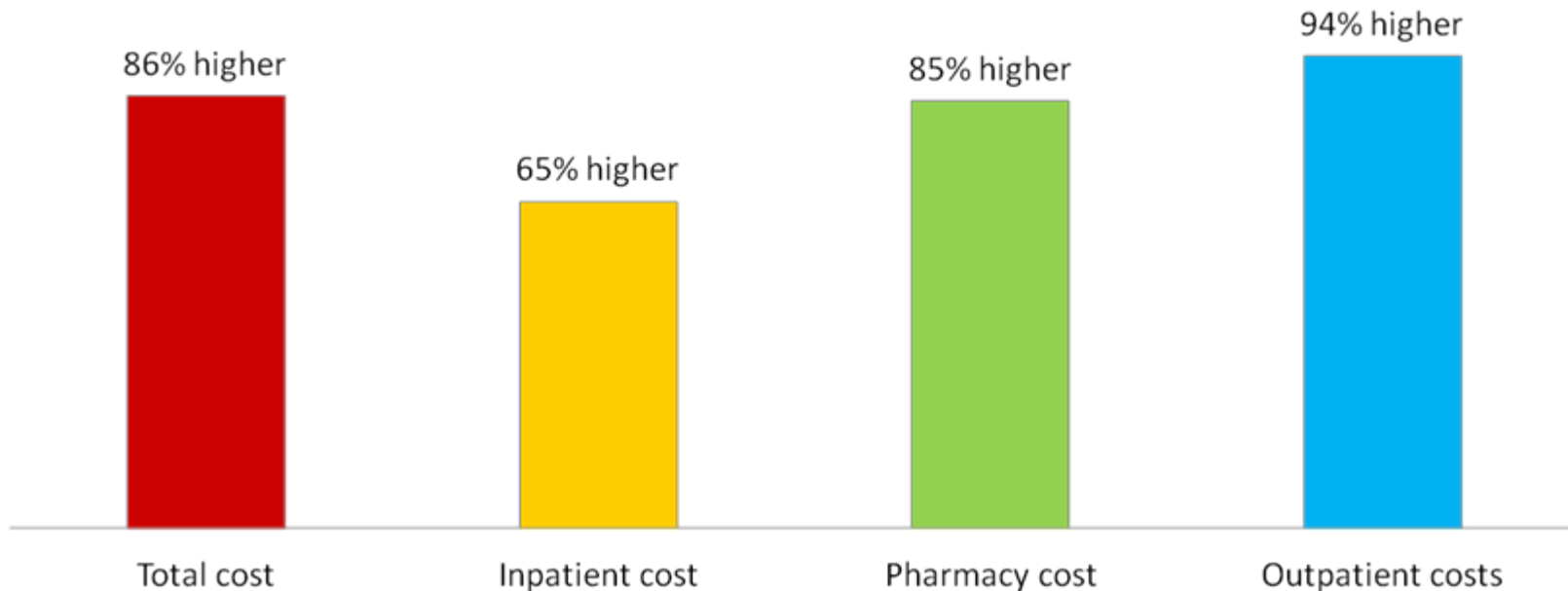
Main reason not taking antibiotics



Healthcare utilization rates are higher for those with CLD

CLD patients have 86% more total healthcare costs than those without Lyme disease. They incur 65% more inpatient costs, 85% more pharmacy costs, and 94% more outpatient costs.

Healthcare costs higher for patients with CLD than for others



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Cost Of Treatment Impact



"I work in a busy Emergency room and I can promise you that if a patient states that they have fibromyalgia, Lyme disease or chronic fatigue syndrome they are quickly and easily dismissed as insane, drug seeking, or hypochondriacs.

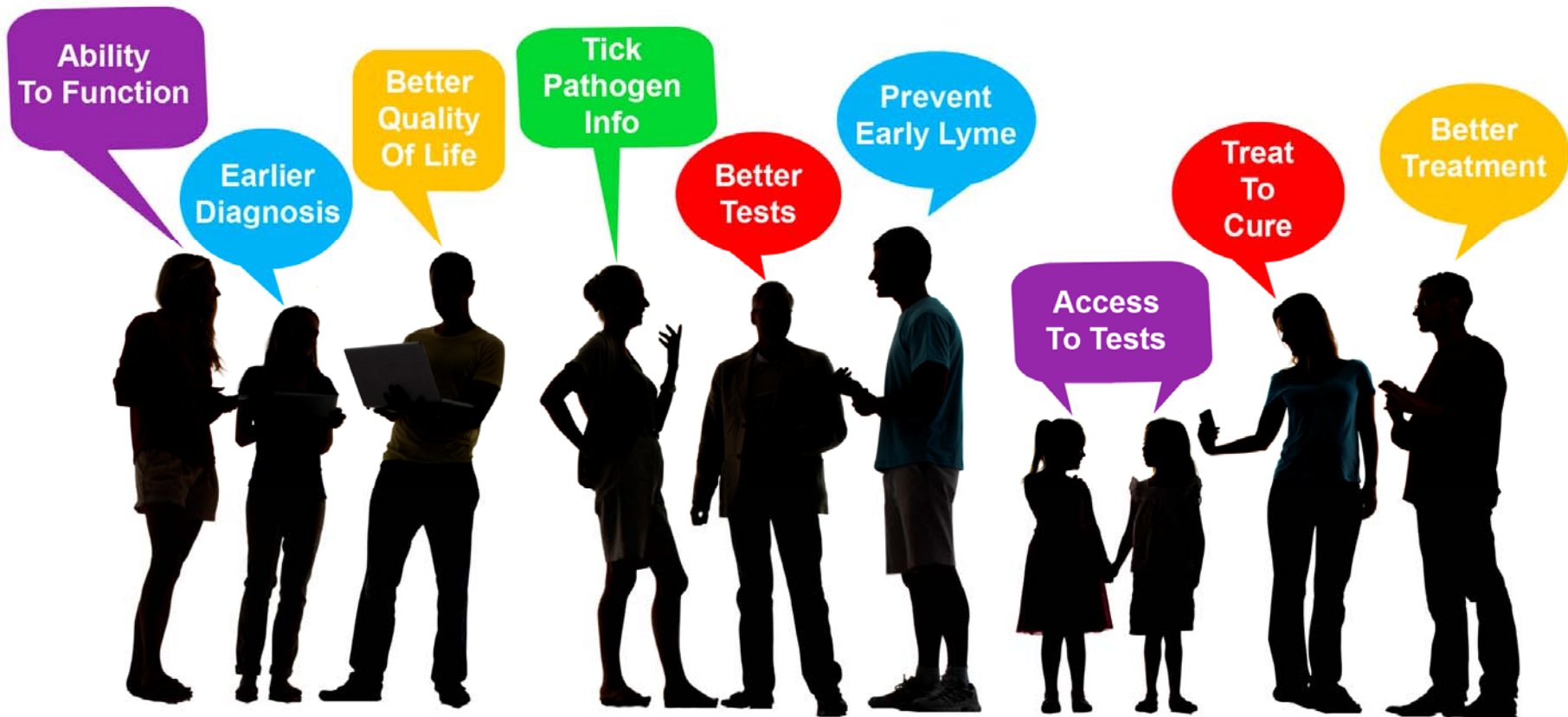
I have seen many highly educated and hard working people taken down and their careers and family lives destroyed by this bacterial infection that should be easily treated but isn't.

Suicide rates are very high in people that have chronic Lyme...I have chosen to keep on fighting and will hopefully someday be better and be able to advocate for people who are unable to advocate for themselves.

I suppose that the cost of treatment is a huge factor in the decision for the CDC to decide to make chronic Lyme a covered and payable disease. If they would just take a look at what they spend for people that are on disability...I think that they would find that it would be cheaper to just pay for the treatment of their bacterial infection and get them back to work!!"

Female, 45, WA

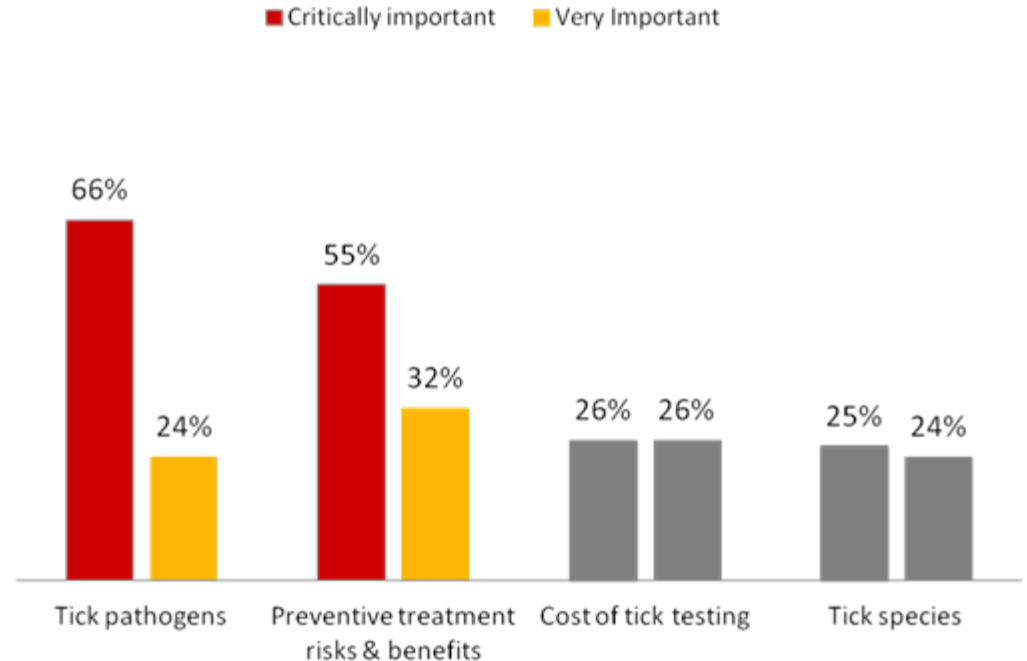
What do patients want?



What is important to patients after tick bite?

1. Patients want to know the pathogens carried by the tick.
2. Patients want to know the risks and benefits of preventive antibiotic treatment.
3. Other factors, like knowing the cost of tick testing and the tick species are not as important.

What's important to know after a tick bite?



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Tick Bites

"I found my tiny deer tick and removed it. Took to my PA and requested testing of the tick, she said they (medical community) don't even do that anymore, if I became ill to come see her then."

Female, 30, NC

*"I was infected on a trip to a Lyme endemic area but live in an area with few infected ticks - **I could not get a local doctor to test or treat for Lyme early on, despite the tick bite and rash.**"*

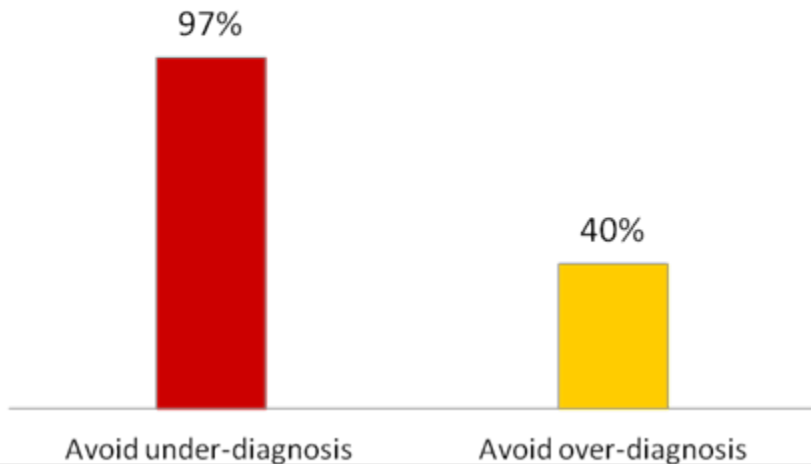
Female, 41, CA



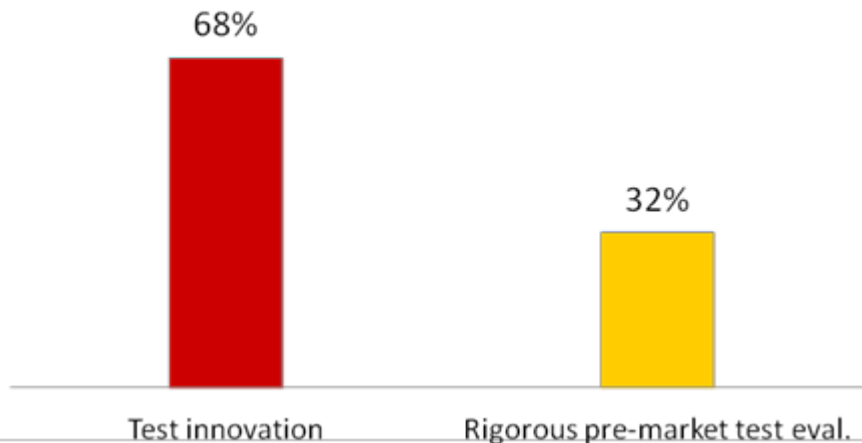
We need to avoid under-diagnosis & foster test innovation

Those impacted by Lyme care most about avoiding under-diagnosis and increasing laboratory test innovation. By a two-to-one choice, participants prefer avoiding the risks associated with under-diagnosis versus over-diagnosis. Persisting Lyme disease symptoms may be caused by a persisting infection, damage to the system, an immune response, or some other cause. No currently available test can detect whether or not bacteria persist after treatment.

It is critically or very important to



It is more important to have



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Faulty Tests Delay Diagnosis

*“Please do something about the faulty testing for Lyme disease by the CDC. The numbers of people suffering from Lyme is rapidly growing. It is maddening that the CDC wants to turn their back on us. I believe I would not be suffering with Lyme now if my physicians would have recognized my symptoms when I first presented to their offices. **Faulty testing and limited physician training to recognize Lyme is the reason I'm in this situation.**”*

Female, 48, FL

*“There is no doubt in my mind that I could have been symptom free if there would have **been better testing** and if my GP would have been knowledgeable about the poor testing and the need for longer antibiotic courses. I can only work 2 days a week now and am still considered disabled.”*

Female, 41, WA

*“I was mis-diagnosed for 6 months because **my ELISA test came back normal but I did have Lyme** and got better with about 4 months of antibiotics”*

Female, 25, MA



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Bad Tests Impact



"I started to feel ill in Fall 2008 after I was bit by a deer tick in NH. I was given a Z-pack in case I may have contacted Lyme 3 days later. Shortly after I started feeling ill... I was a Division I cross-country and track athlete, but now I was struggling to run 30 minutes when the year before I was one of the top runners on the team.

***I was tested for Lyme with the ELISA and it came back negative.** The doctors said there was nothing wrong and to just "eat more and sleep more." But I knew something was really wrong. My senior year of college I didn't even qualify for the track team.*

*I saw many, many doctors. One tested me two times with the ELISA for Lyme... When both tests were **negative**, planned to diagnose me with chronic fatigue syndrome and give me a stimulant. Then I went to a general practitioner who said it sounded like Lyme disease and **that the ELISA was maybe 60% accurate; he tested me with the Western blot which was positive.** It's been a journey since then, but I am thankful."*

Female, 25, MA

It's important to give patients *everywhere* the option to test

Over 90% of participants regarded it as critically important to give patients with symptoms consistent with Lyme disease the option to be tested even in non-endemic areas

- 47% report that testing was delayed because they were not in an endemic area
- 60% report that this delayed their ultimate diagnosis
- 69% report the delay in diagnosis was for more than a year

“Diagnosis was my biggest problem. Doctors refused to test because there was ‘no Lyme in Virginia’. Despite the fact that the vets were seeing a lot of Lyme in the dogs. I had to go to another state to be tested.”

Female, 60, VA

“I was sick for a very long time and no one checked me for Lyme. Now I have chronic Lyme. No provider asked me if I had traveled to a high Lyme incident place, which I had!”

Female, 49, MS

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Non-endemic

“I don't live in one of the 14 states that are considered to have Lyme in greater than 20% of the tick population. Therefore, when I went to the ER with an engorged tick on my neck, I was refused treatment, and told to go home and wait for symptoms. I was told that symptoms may come in the form of the flu or a rash. I had neither, so I thought I was fine.

However, not even a year later, I had developed insomnia, tachycardia, and a heart valve prolapse. At the time, I had no idea that those are Lyme disease symptoms. . . Having undiagnosed Lyme for over 20 years has caused me a mess of health problems. My life is ruined. If only I could have just had that simple bottle of prophylactic doxy all those years ago in the ER my life would be so different right now. One bottle of doxy before this went systemic could have saved me from a true nightmare...

*Please change the guidelines. **Anyone, regardless of the state they live in should be able to get Lyme treatment.** Doctors need to be educated on this and be willing to test people for it. We need accurate testing. Please find a cure for the millions that are suffering. This disease is devastating. I can barely function anymore.”*

Female, 34, ID



Treat early Lyme disease to cure

- Almost all (99%) of participants considered it very or critically important to improve success rates for treatment of early Lyme disease.
- 41% would strongly prefer a longer treatment duration to improve treatment success in early Lyme disease.
- 58% consider it very important to be told the benefits and risks of longer and shorter treatment options and given the opportunity to choose between them.
- Only 1% preferred short-term treatment to avoid the potential additional risk of medication side effects.

“I had a "bull's eye" rash and was treated with 3 weeks of doxy. Over time I got worse and worse and was told I couldn't possibly still have Lyme since I was initially treated with the 3 weeks of antibiotics. Now years later my life is ruined because I didn't get long enough treatment and doctors didn't want to listen or believe me.”

Female, 34, MA

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Treat To Cure



*"I am shocked and upset that our family doctor, who is very well respected and educated, didn't offer referral to a Lyme specialist. **After 21 days of rapid decline under the CDC standard protocol of oral antibiotics, he advised to stop antibiotics, said there is nothing that can be done. The Lyme disease should be cured by now.** Then specialists, who know that higher doses of antibiotics are necessary, are fearful of losing their license due to the Lyme controversy. **Patients are powerless and denied real treatment.** It's very sad and shameful for the American medical community."*

Male, 34, CT

*"The current CDC guidelines failed me. I was bit by a tick in 2001 and developed the typical bull's-eye rash. **I was immediately diagnosed with Lyme disease and given two weeks of antibiotics. I was told that would be the end of it and it would cure the problem.** 10 years later after trying to figure out what was wrong with me, we discovered that the Lyme had not gone away and was keeping me sick."*

Patient, 44, RI

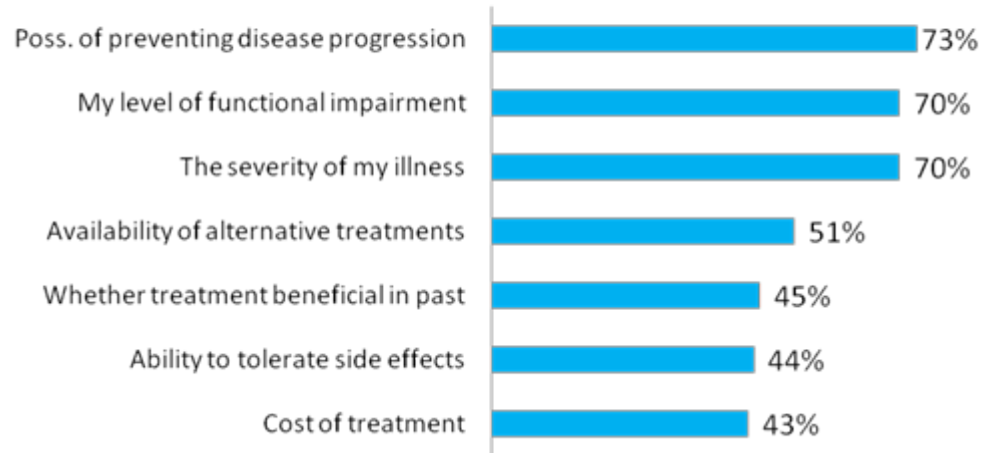
Patients value treating to cure over symptom relief alone

Most participants suffer from severe or very severe symptoms. No diagnostic test can determine whether or not any underlying infection has been eliminated. Given this uncertainty, patients were asked whether they valued symptomatic relief alone, the opportunity to treat potential underlying infection, or both options.

More than 90% valued giving patients the option to treat a potential infection to cure or providing patients with treatment options. Over 50% consider the provision of symptomatic relief alone as either less important or not important.

The chart below shows factors participants consider critically important in deciding to proceed with additional or more risky treatments.

Important factors in treatment decisions



Treatment Options and Choice

Individualized care and informed participatory treatment decisions are important to patients. 85% or more of participants believe it is very or critically important that:

- Patients be informed about both the IDSA and ILADS treatment approaches, the uncertainty regarding the best way to treat persisting symptoms, the risks and benefits associated with treatment options
 - Patients be provided with choices among treatment options
 - Physicians be allowed to use their professional judgment
 - Treatment approaches be individualized
 - Patients be involved in determining whether potential treatment benefits outweigh risks
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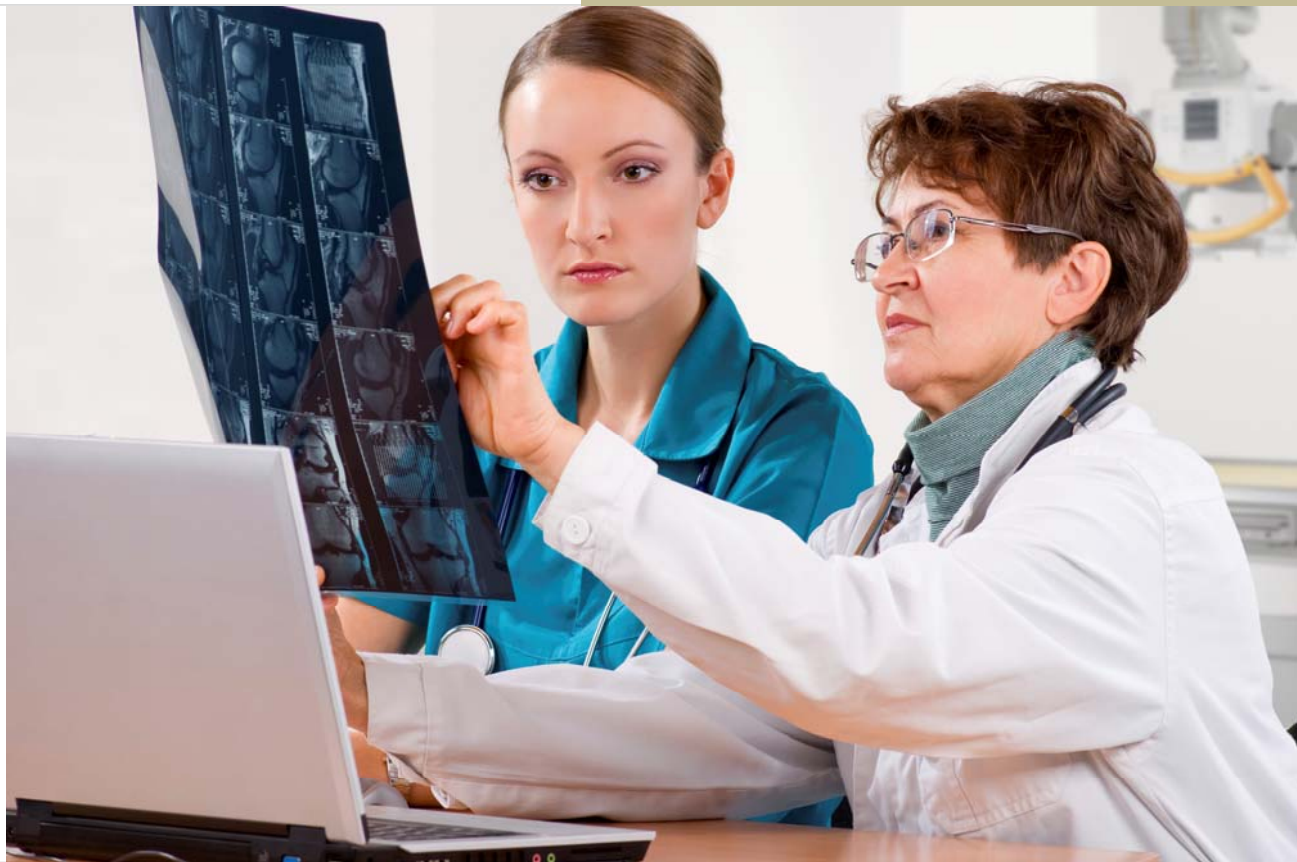
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Treatment Options & Choice

“My life has been destroyed by this disease, and had I not finally been treated I may well have died.

***Treatment has allowed me to regain some of my life, but I will never be able to practice again in a clinic.** I am angry at every doctor who missed the diagnosis and at the medical community who are ignoring an epidemic, but mostly I am sad. I am sad for all the brilliant minds that have been lost to this disease and will never make the breakthroughs they could have made. I want to scream at the top of my lungs “DO SOMETHING” to stop this epidemic.”*

Female, 62, MN



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Treatment Options & Choice

*“I'm the one devastated by this disease, and the truth is, you don't know for certain how to treat it. With a condition fraught with so much uncertainty and unknown, the most we can be offered is the state of all available knowledge (even if they oppose each other), access to (and insurance that covers) all treatment approaches, and **the freedom to make our own choices.**”*

Female, 51, OR

*“Until unbiased clinical studies are completed I believe that **physicians should be able to treat patients with tick-borne illnesses as they deem appropriate.** It will be difficult for any clinical studies to be carried out without a major breakthrough in testing for Lyme disease and other co-infections.”*

Female, 62, MN



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Treatment Options & Choice



“I am functioning but my life as a typical teenage boy does not exist due to Lyme disease. My parents spent \$15,000 to get me back on my feet. My cardiologist wouldn't let me go to school for 9 months. I was isolated at home due to impact on my heart from Lyme disease. Please take this disease seriously, encourage more doctors to become LLMDs & demand insurance companies to cover Lyme disease treatment.”

Male, 16, CT

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Treatment Options & Choice

*"I've made significant progress with individualized treatment, but **I have had to FIGHT for it every step of the way and it has cost me my dream job in NYC, my retirement, my savings, and my social life.** Lyme patients deserve better advocates in the medical field."*

Female, 31, IL

*"Patients **MUST** be allowed to be **informed about possibility of Lyme disease at the onset of classic symptoms with or without the Bull's eye rash and be offered testing** for it. Patients who miss the 30 day window after a tick bite need to be referred to experienced, holistic, Lyme-literate physicians so that prolonged antibiotic therapy with resultant worsening of the disease is avoided.."*

Female, 55, AL



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Treatment Options & Choice

*“When you have Lyme possible side effects from treatment don't seem to matter because you are so sick. It's just like cancer treatment. Is that good for you?, no, but will it save your life? You see where I am going. Also to take this survey was very hard to read, focus and concentrate. **You can only understand how someone with Lyme feels if you have it.** It is mind boggling. Thank you for conducting this survey, it makes me feel like someone is listening. :)”*

Female, 35, UT

*“Although the side effects of antibiotics may concern the health profession....The risk of delaying treatment or undertreating someone comes at a much higher cost. **Lives are RUINED by this disease.....I have lost 3 years of my life so far and I do not know if I will ever get well. There needs to be more discussion about the co infections associated with these tick bites....and how to test and treat those as well.**”*

Female, 52, CT



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Treatment Options & Choice

*“A patient is the best source providers have to what is happening inside the patient's own body. Therefore, it is imperative that each patient be given as much information as possible and the have a large amount of input into his or her individualized treatment plan. Lyme disease and its coinfections are elusive in diagnosis, treatment and predictability. Patients are the experts of this disease not the physicians. **It is so important that they are listened to, given further education, and taken seriously, or we will never come to better understand this disease in all its complexity.**”*

Female, UT



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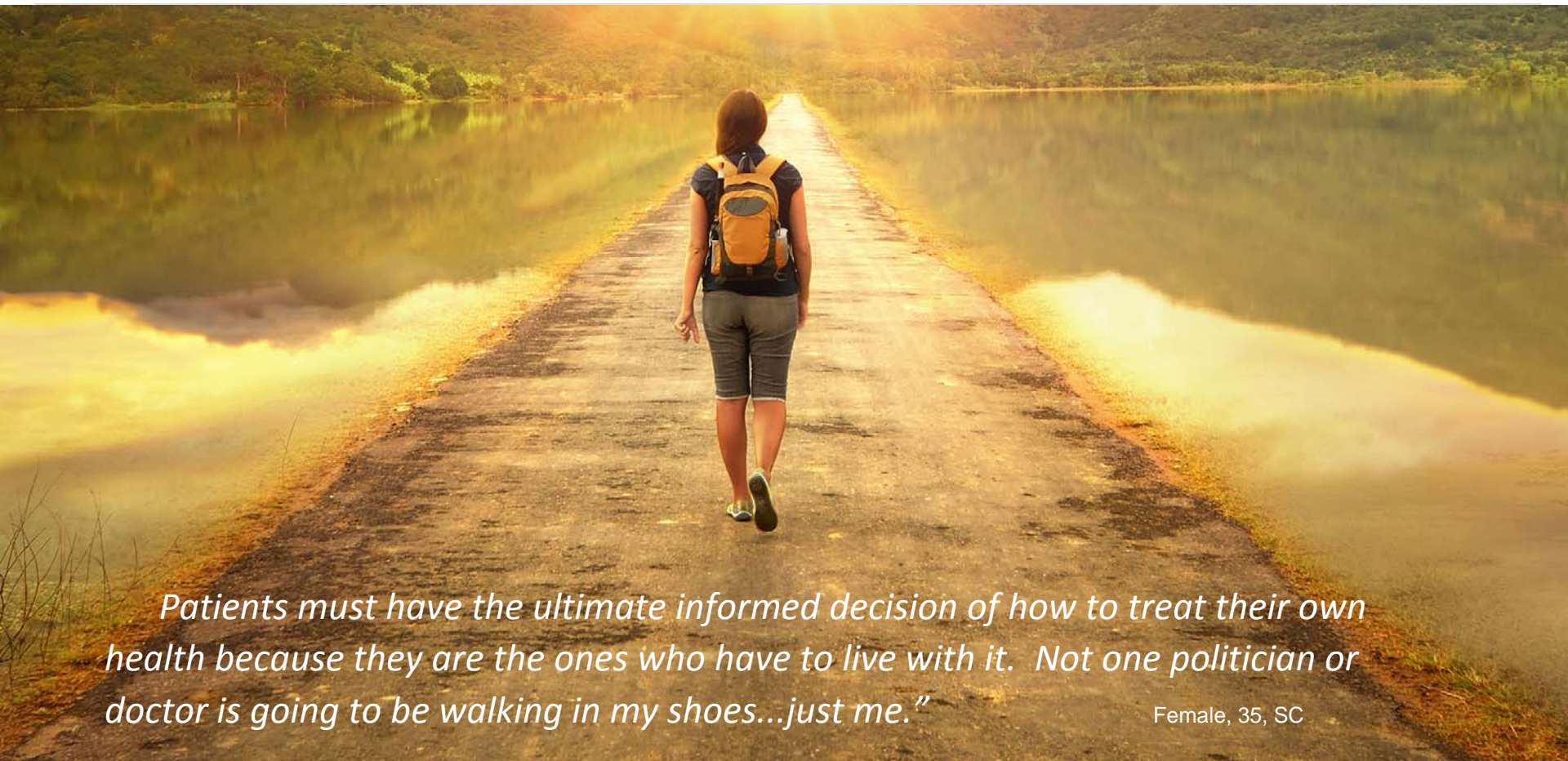
Treatment Options & Choice

*“I spoke with an oncologist in passing. He stated that cancer care has not progressed much in 20 years, the big picture. What you hear on TV is not the case that he sees day to day. **Yet they still try and many die. I see no problem if the patient chooses Treatment, Hospice, both.** I listened to an hour CDC seminar on persistent Lyme. I was amazed at the researchers finding results that it does exist. I was more amazed, that at the end of the seminar, one researcher wanted to discredit all the great info. It was pathetic. Until I get another diagnosis. I will treat the best way I can. **Like AIDS in the 80-90 people had to meet in parking lots to exchange antivirals.** What a disgusting mess.”*

Male, 55, TX



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Patients must have the ultimate informed decision of how to treat their own health because they are the ones who have to live with it. Not one politician or doctor is going to be walking in my shoes...just me."

Female, 35, SC

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This survey was conducted over the internet in the United States between March 24th and April 23rd, 2015. It drew over 6,100 responses in that one month period.

Over 1,787 individuals made open ended comments in addition to completing the questionnaire. Representative comments were selected to include in this report. Photos used in this report are representational only and do not depict actual survey respondents.

The survey was answered by patients, parents of children affected by Lyme and spouses of those with Lyme disease. The average age was 47 and 82% of respondents were female.

This survey is part of a series of surveys of Lyme disease patients conducted by LymeDisease.org. Two of the previous surveys were published in peer review journals and can be access [here](#) and [here](#). [Find out more about LymeDisease.org surveys.](#) Contact the lead author, Lorraine Johnson, JD, MBA at lbjohnson@lymedisease.org.



A LymeDisease.org Survey