

Mary Beth Pfeiffer



# LYNNE

The First Epidemic  
of Climate Change

# This Epidemic is NOT...

What you may think

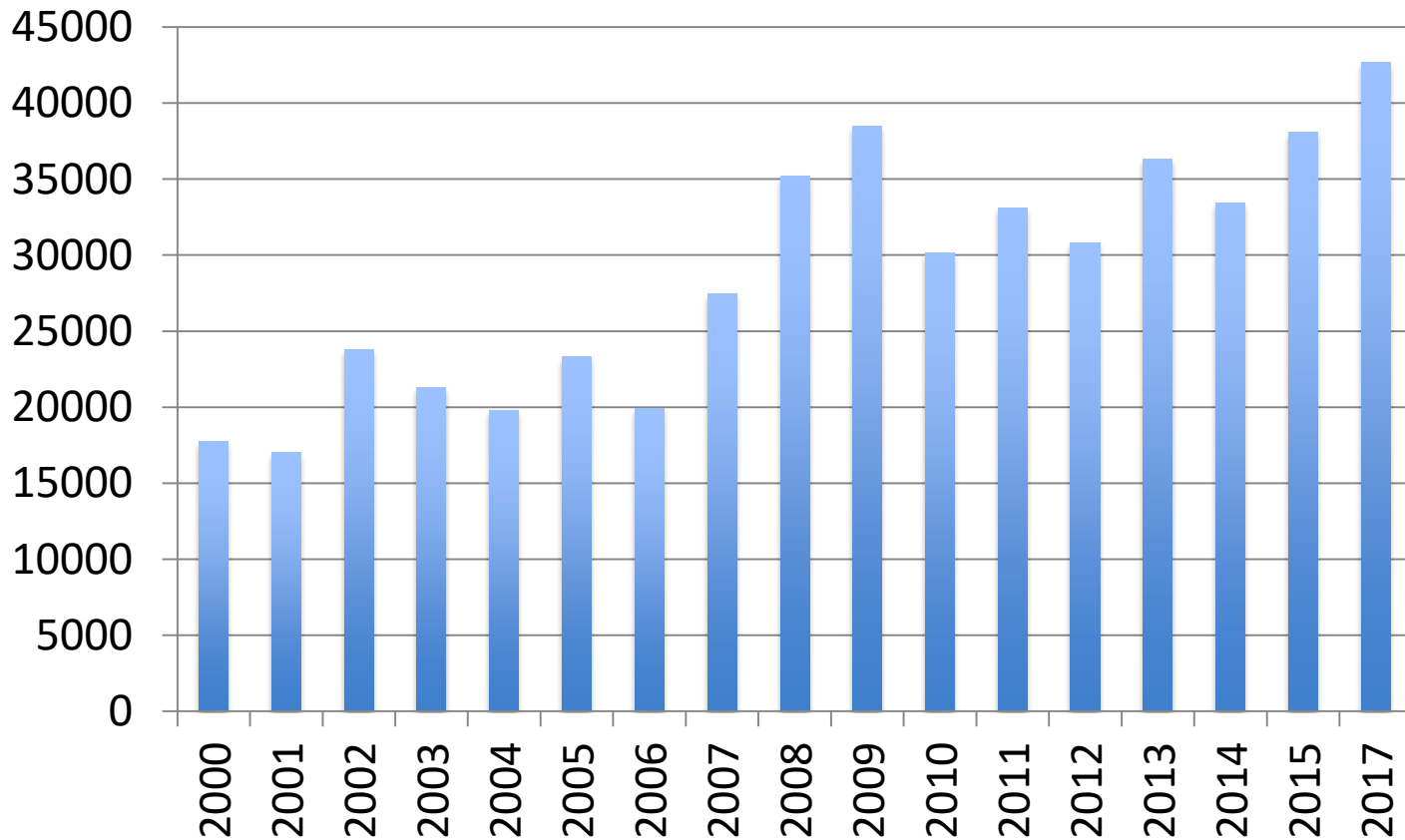
Managed well

Small

***Under control***

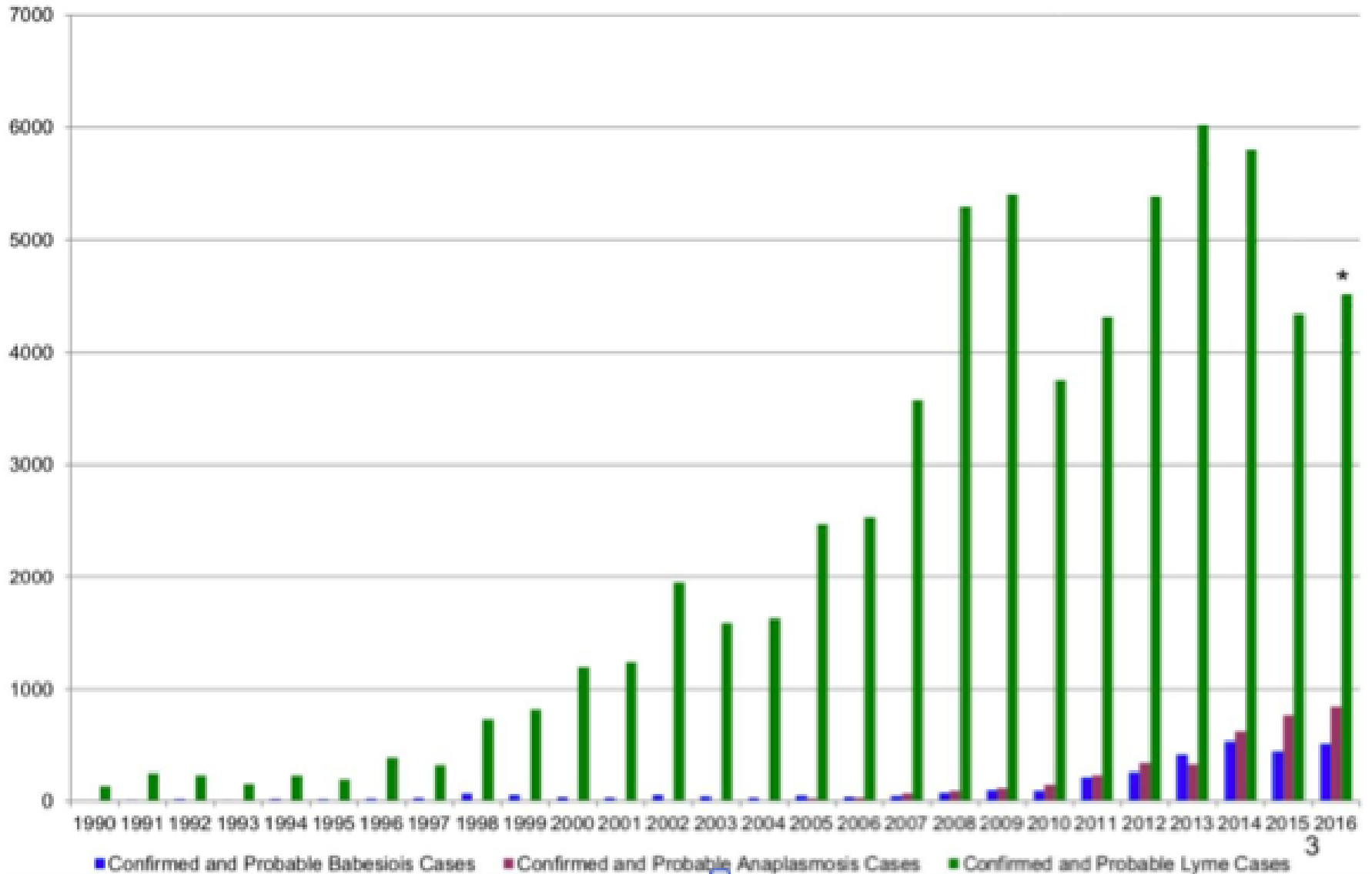
# First, the problem

Lyme is **soaring**

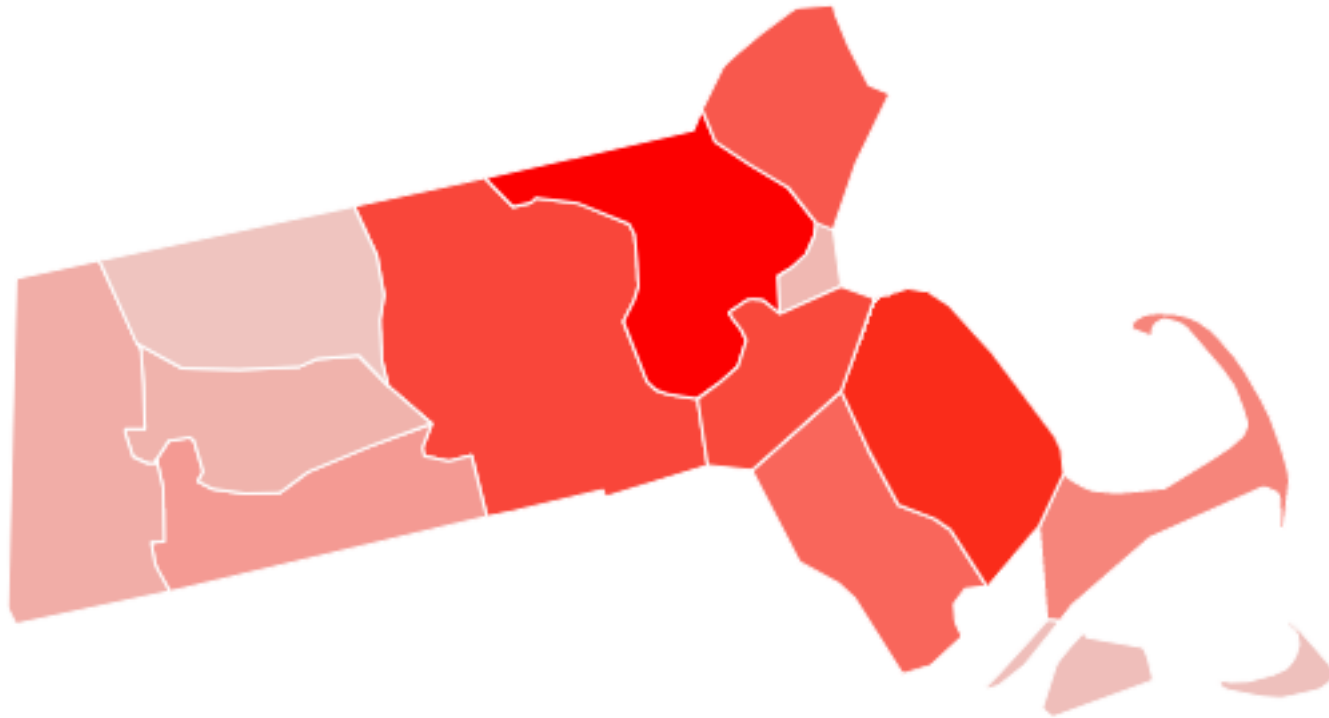


**US cases: 17,000 in 2000 to 43,000 in 2017**

# In Massachusetts too...



# Lyme in Massachusetts\*\*



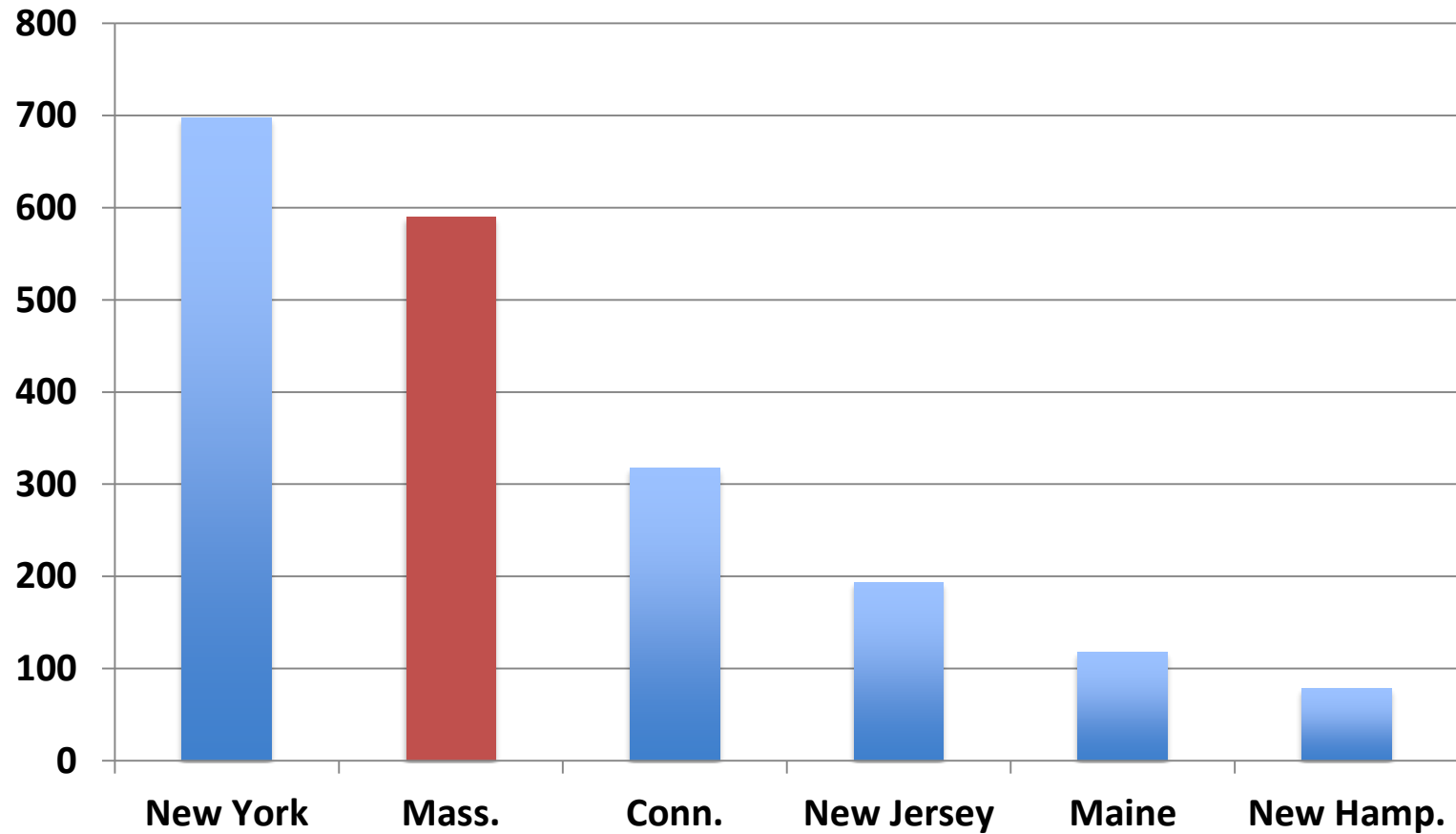
**49,680**

Total cases of lyme disease confirmed in Massachusetts (2000 to 2016)

\*\*Actually: ~500,000

*Source: 2013 Mass.gov report*

# Not just Lyme: Babesiosis



*Source: CDC, 2017 data*

This Epidemic  
is...

Worldwide  
Climate driven  
Underestimated  
Still unfolding





# Ticks carrying multiple diseases are 'taking over' Long Island

By Lauren Steussy

September 17, 2019 | 2:17pm | Updated



Shutterstock



## MORE ON: **TICKS**

**Maine reports first case of rare, deadly tick-borne virus since 2017**

**Tick latched on man's**

Lyme disease isn't the only awful illness ticks are capable of transmitting.

Superticks can carry up to four different diseases at a time, including Lyme disease. And these insects of mass destruction are becoming especially abundant in Long Island, according to a study [published this month in the journal PLoS](#)



# Killarney National Park, Ireland



Photo by James Pembroke



Germany

France



Mairie de Paris logo

Tiques, chenilles, aoûtats, frelons...  
avec les beaux jours, les insectes sont de retour



## Attention aux tiques

Les tiques sont des parasites qui se nourrissent de sang et qui peuvent transmettre des maladies à l'homme, notamment la maladie de Lyme.

**Comment les repérer ?**

Les tiques sont des acariens visibles à l'œil nu, mesurant entre 1 et 3 mm. On les trouve dans les bois ou les herbes hautes. Lorsqu'elles piquent, elles restent fixées à la peau pendant plusieurs jours. Leur piqûre peut être indolore : il faut donc s'inspecter soigneusement le corps au retour de chaque promenade.

**Que faire en cas de piqûre ?**

C'est pendant la piqûre que la tique risque de transmettre ses maladies. Il est indispensable de la retirer le plus tôt possible avec un tire-tique (disponible en pharmacie). Ne vous grattez pas, afin de ne pas l'écraser ni la casser !

Après une piqûre ou en cas de doute (apparition de rougeurs, douleurs, fièvre, maux de tête notamment), **consultez un professionnel de santé !**

TIQUE L'INFO  
Mairie de Paris  
www.paris.fr

TIQUE L'INFO  
Mairie de Paris  
www.paris.fr

Netherlands

# Wij attenderen u in dit bos op het gevaar van:

**Vossenlintworm**  
*Infectie mens en hond*



**Eikenprocessie rups**  
*Veroorzaakt: **jeuk***



**Teken**  
*Veroorzaakt: **Ziekte van Lyme***



**Vallend hout en takken**



**Betreden op eigen risico!**

**Honden  
aan de lijn!**



**Paarden  
geen toegang!**



Australia

**‘Under-diagnosis of early Lyme disease and physical damage at an advanced stage are a huge problem.’**

--Dou, 2015, study of 800 residents in China





‘Macabre as a  
Stephen King  
horror novel,  
except...’

--Garth Ehrlich



Graphic by Toni Miraldi

# About me



\*30+ years

\*Many awards

\*Objective

\*No vested interest





# What I looked for in stories\*

- Incompetence or worse
- Injustice
- Waste of money

\*I didn't expect this in Lyme disease.

# My journey

Highest Lyme rates.

Forget ticks.

Or patients.

**Focus on antibiotics.  
Doctors.**

Doctors helping the  
sick.

## ANTIBIOTICS FUEL DEBATE OVER LYME

5 doctors  
targeted;  
chronic  
treatment  
at issue

By Mary Beth Pfeiffer  
Poughkeepsie Journal

Enemy No. 1 in the war on Lyme disease is a tiny tick that has put the mid-Hudson Valley at the epicenter of a global health threat.

But the prime target of some is not an army of arachnids, as ticks are known. Instead, in this bull's-eye is a handful of doctors — doctors who dispense long-term antibiotics for the illness. At least five, including two in Dutchess County, are under investigation by state licensing officials, the Poughkeepsie Journal has exclusively learned.

While officials contend they do not investigate physicians "simply because 'traditional' treatment protocols (two to four weeks of antibiotics) are not followed," the medications are at the heart of a vitriolic and far-reaching debate over how best to care for advanced Lyme disease, according to interviews with scientists, physicians, patients and their advocates.

The disagreement has marked the disease as a political and scientific quagmire, these people said. Most

AN EXCLUSIVE JOURNAL  
SPECIAL REPORT



Dina Rosado, 44, of Highland receives her daily intravenous antibiotic treatment for Lyme disease at Vassar Brothers Medical Center, Poughkeepsie. Without it, "I don't know what condition I would be in," she said.  
SPENCER AUNGLEY/POUGHKEEPSIE JOURNAL

A scourge of ticks

LYME DISEASE

in New York State...

The chart shows reported Lyme disease cases in New York State for the last decade. In 2008, the definition



ABOUT THIS SERIES

This is part 2 in a Poughkeepsie Journal series on Lyme disease. In three months of research, the Journal spoke to scientists,

# How we got here

## Myths

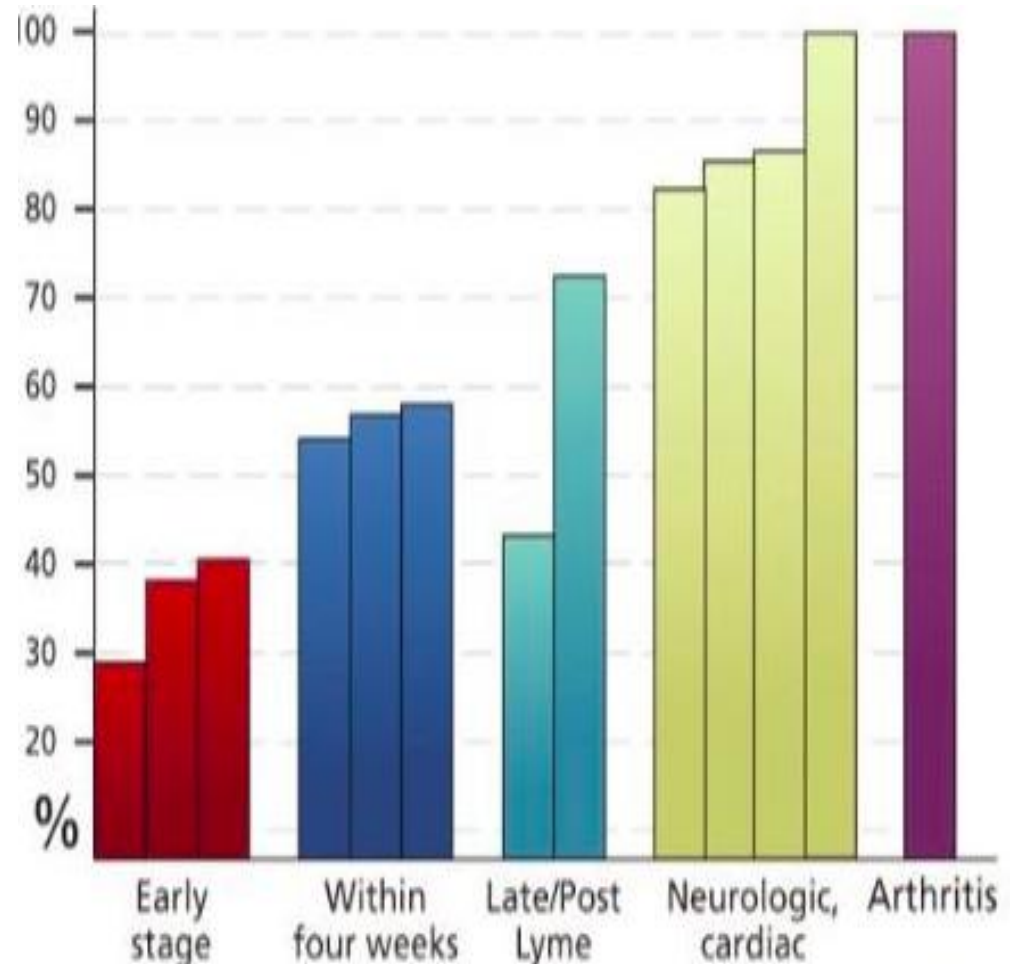
#1 The test works.

# Don't trust the test\*

\*Poor studies...

“Complex, technically demanding, difficult to interpret.”

- Arbitrary
- Requires waiting
- Biased studies



Source: CDC Tutorial for physicians, BJ Johnson (quote)

# \*Don't trust the studies

'The data in this review **do not provide sufficient evidence** to make inferences about the **value of the tests** for clinical practice.'

78 studies – all flawed

*Source: Leeflang et al, 2016*

Don't wait

This nasty spirochete:

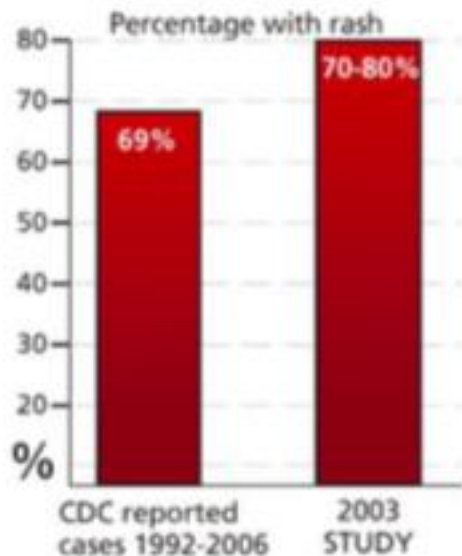
- Disseminates
- Disables immune response
  - Changes shape
  - Goes dormant, **persists**

*“Borrelia is a really, really interesting microorganism. It has a huge brain. It outsmarts people.”*

# But you have the rash...

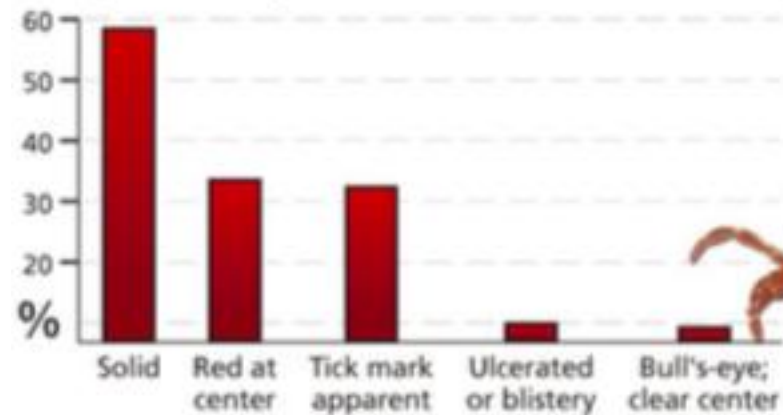
## WHAT IF THERE IS NO RASH?

Early stage Lyme can be diagnosed without a test if there is a rash. However, some people do not get the rash.



## WHAT IF THE RASH ISN'T TYPICAL OF LYME?

Only a minority of rashes are the classic bull's-eye.



CDC: "In the absence of EM, all other manifestations of Lyme disease require serologic analysis to confirm the diagnosis."

**IN THE UNITED STATES DISTRICT COURT  
FOR THE EASTERN DISTRICT OF TEXAS  
TEXARKANA DIVISION**

LISA TORREY, KATHRYN KOCUREK  
Individually and on behalf of the Estate of J.  
DAVID KOCUREK, PH.D., LANA BARNES  
Individually and on behalf of the Estate of AL  
BARNES, AMY HANNEKEN, JANE  
POWELL, CAROL FISCH, CHRISTOPHER  
VALERIO, STEVEN WARD, RANDY  
SYKES, BRIENNA REED, ROSETTA  
FULLER, ADRIANA MONTEIRO  
MOREIRA, JESSICA MCKINNIE, KRISTINE  
WOODARD, GAIL MEADS, DR. MICHAEL  
FUNDENBERGER, GAYLE CLARKE,  
ALLISON LYNN CARUANA, CHLOE  
LOHMEYER, MAX SHINDLER, TAWNYA  
DAWN SMITH, Individually and as Next  
Friend of MONET PITRE, MIKE PEACHER,  
Individually and as Next Friend of ASHLEIGH  
PEACHER, ALARIE BOWERMAN,  
Individually and as Next Friend of ELISA  
BOWERMAN, EMORY BOWERMAN, and  
ANAIS BOWERMAN

Plaintiffs

v.

INFECTIOUS DISEASES SOCIETY OF  
AMERICA, BLUE CROSS AND BLUE  
SHIELD ASSOCIATION, ANTHEM, INC.,  
BLUE CROSS AND BLUE SHIELD OF  
TEXAS, AETNA INC., CIGNA  
CORPORATION, KAISER PERMANENTE,  
INC., UNITED HEALTHCARE SERVICES,  
INC., UNITEDHEALTH GROUP  
INCORPORATED, DR. GARY P. WORMSE  
DR. RAYMOND J. DATTWYLER, DR.  
EUGENE SHAPIRO, DR. JOHN J.  
HALPERIN, DR. ROBERT B. NADELMAN,  
DR. LEONARD SIGAL, AND DR. ALLEN  
STEERE

Defendants



# First order of business: Deny care

48. In the 1990's the Insurance Defendants decided that treatment of Lyme disease was too expensive and "red-flagged" Lyme disease. The health insurance industry made a concerted effort to deny coverage for treatment of Lyme disease. The Insurance Defendants enlisted the help of doctors who were researching, not treating, Lyme disease. The Insurance Defendants paid these IDSA Panelists large fees and together they developed arbitrary guidelines for testing Lyme disease.

49. Once these arbitrary guidelines were decided, the Insurance Defendants could, and did, deny coverage for patients if they did not meet their new stringent Lyme testing protocols. Since most Lyme patients would not test positive under the new protocols, the Insurance Defendants could deny coverage for many people suffering from Lyme disease.

# Trusting the Test

Q. Okay. So what's the significance to you as a treating doctor of the fact that the antibody test was negative for Lyme?

A. That he didn't have Lyme at that time.



Joseph  
Elone, 17

# Myth #2

## We can cure Lyme disease

**Wormser 2019:** 14 days of amoxicillin

- -**Highly effective** and **well tolerated**
- -**Uniformly successful** in resolving rash
- - 'No patient developed **an objective** ... manifestation of Lyme disease'

**And yet:**

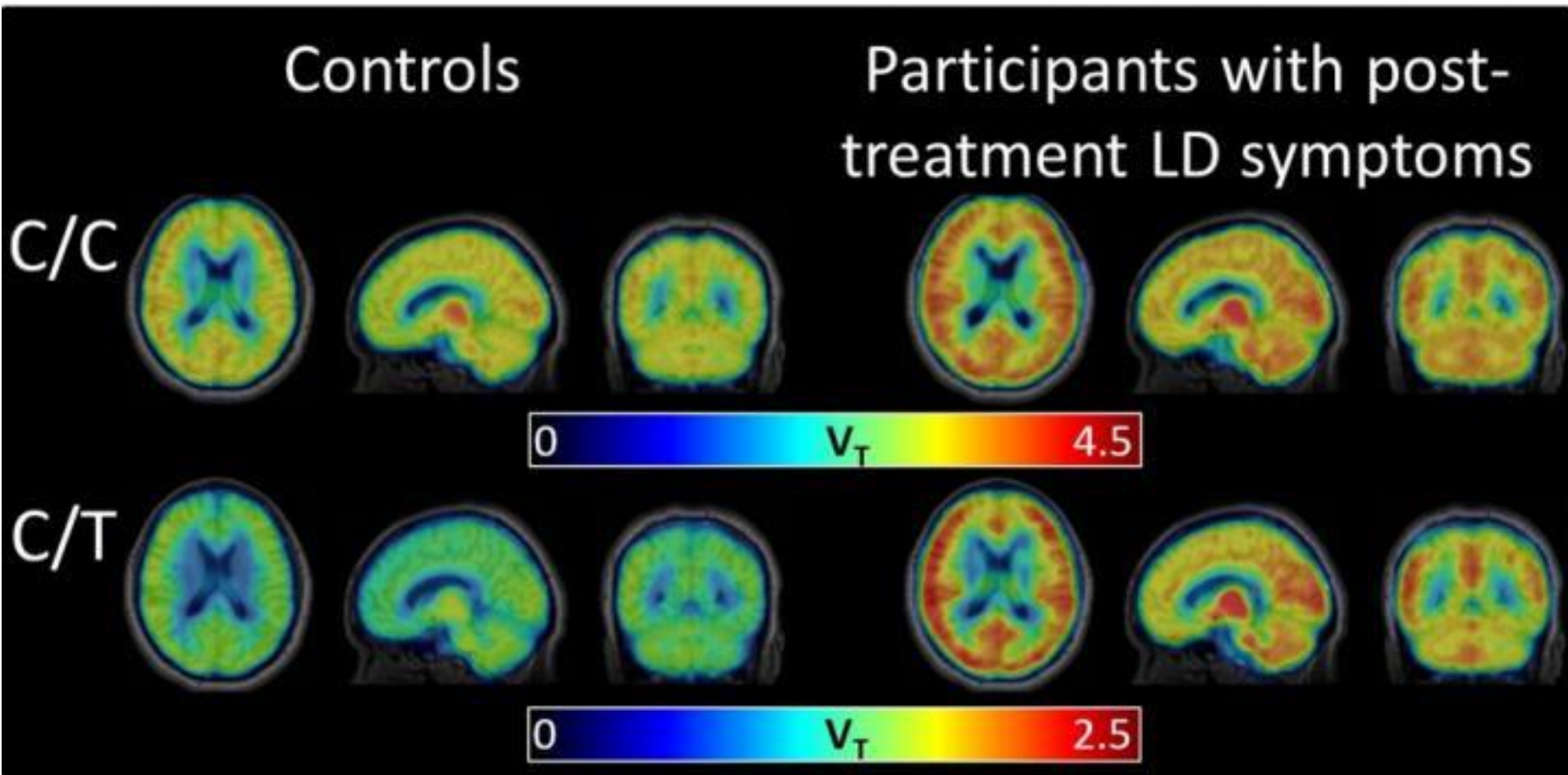
- 'Evidence of PTLDS was found for **16.7%** of the 24 subjects...'

# After treatment...

*'Approximately **10 to 20% of patients** treated with... 2-4 week course of antibiotics will have lingering symptoms of fatigue, pain, or joint and muscle aches.'* --- CDC

- That's 42,000-84,000 in 2017
- That's among **EARLY** treated
- Late-treated damage: **'severe'**

# The damage is real



Source: *Journal of Neuroinflammation*, Johns Hopkins

# Few, bad trials

- ‘Underpowered’
- Positive effects minimized
- Negative effects exaggerated
- Same approach **over and over**

**Antibiotic retreatment of Lyme disease in patients with persistent symptoms: a biostatistical review of randomized, placebo-controlled, clinical trials.**

DeLong AK<sup>1</sup>, Blossom B, Maloney EL, Phillips SE.

**DISCUSSION:** This biostatistical review reveals that retreatment can be beneficial. Primary outcomes originally reported as statistically insignificant were likely underpowered. The positive treatment effects of ceftriaxone are encouraging and consistent with continued infection a hypothesis deserving additional study. Additional studies of persistent infection and antibiotic treatment are warranted.

OPINION / COMMENTARY

By Mary Beth Pfeiffer

# The peril of chronic Lyme disease

CDC is ignoring growing science of the affliction's recurrence and persistence.

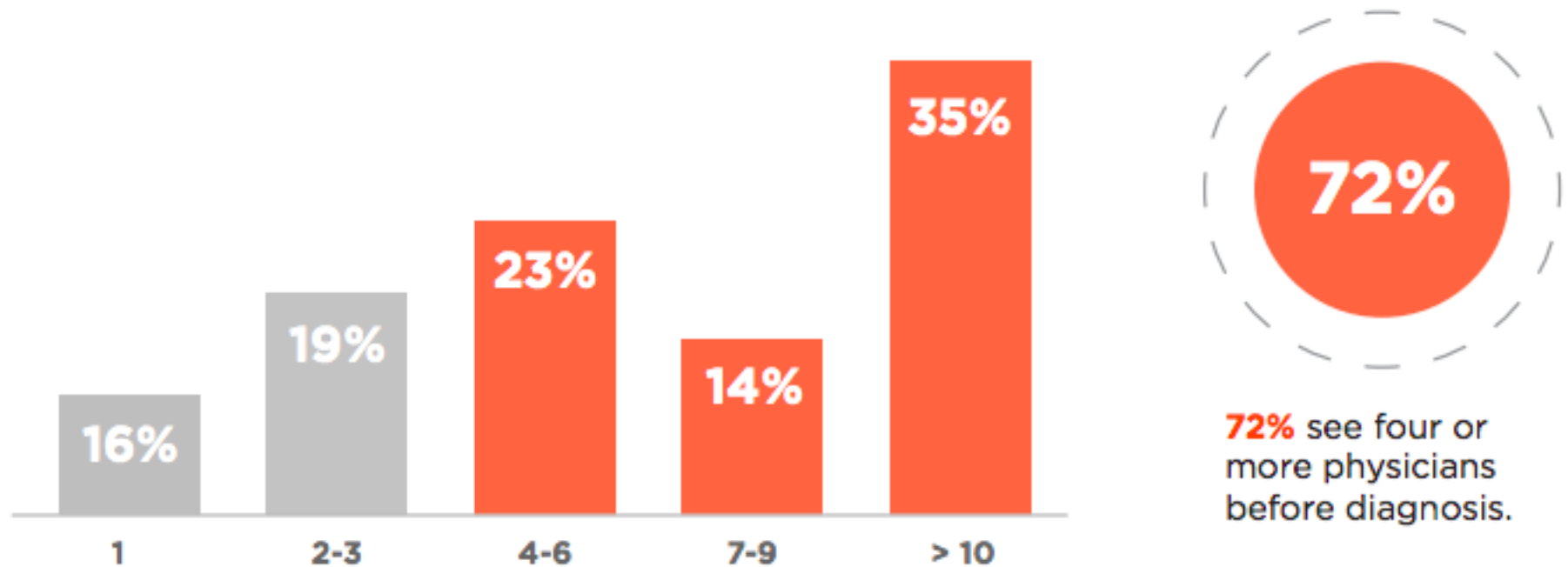
## Risks of ABX exaggerated

- 21 years
- 6 studies
- 4 on single cases

*Source: US Centers for Disease Control*

# The upshot of the dogma: Care delayed

How many physicians before diagnosis?



Source: MyLymeData, 12,000 late-Lyme patients



# 'No big deal'

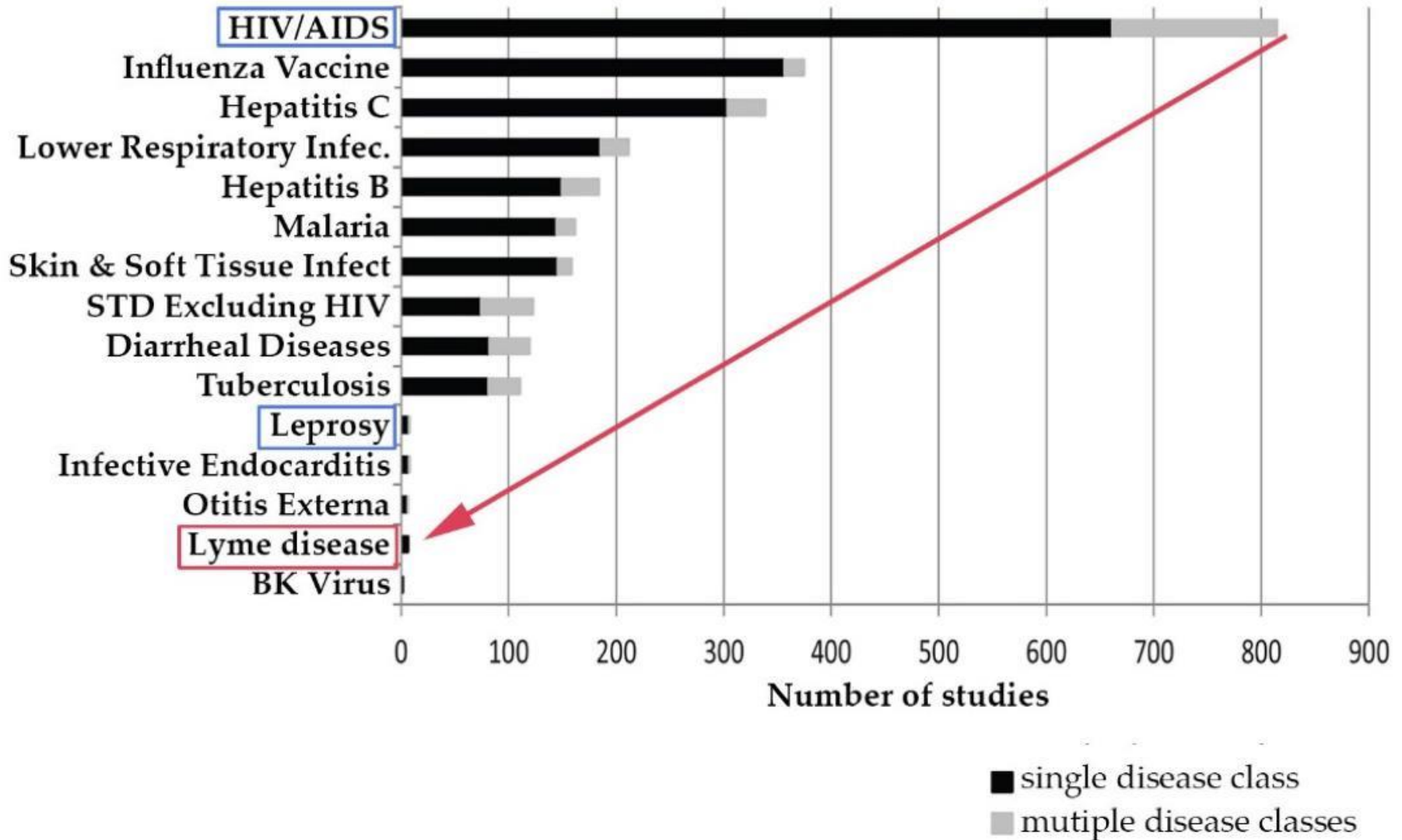
**Lyme disease: 70 Studies**

**AIDS: 11,666 Studies**

*Source: Clinicaltrials.gov Sept. 10, 2019.*

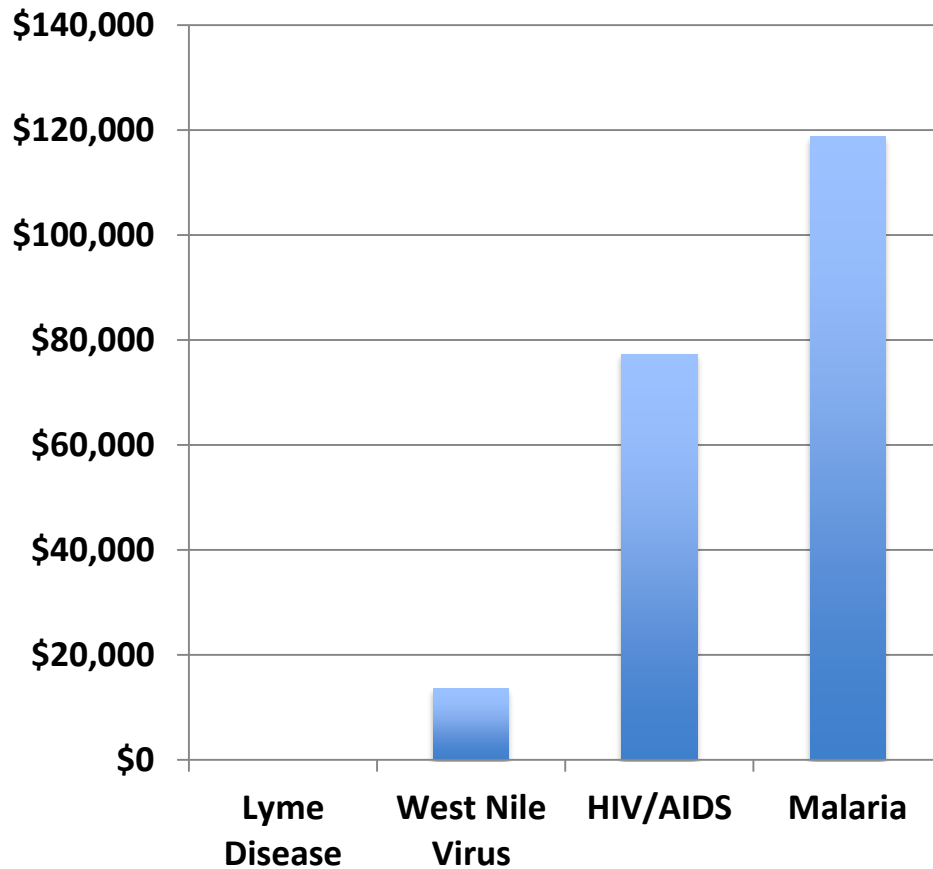
*Current studies: Lyme 26; AIDS 1,522*

## Number of clinical trials in infectious diseases



# Little \$ or research

NIH spending per case



## Little for Lyme

Lyme Disease	\$70
West Nile Virus	\$13,600
HIV/AIDS	\$77,312
Malaria	\$118,824

Source: NIH figures, MBP analysis

# Antibiotics aren't the answer.

What is?

**Recognition. Research.**

- \*A new test for quick DX.
- \*Treatments that may cure.
- \*Control of ticks in the wild.



# What's wrong with this picture?

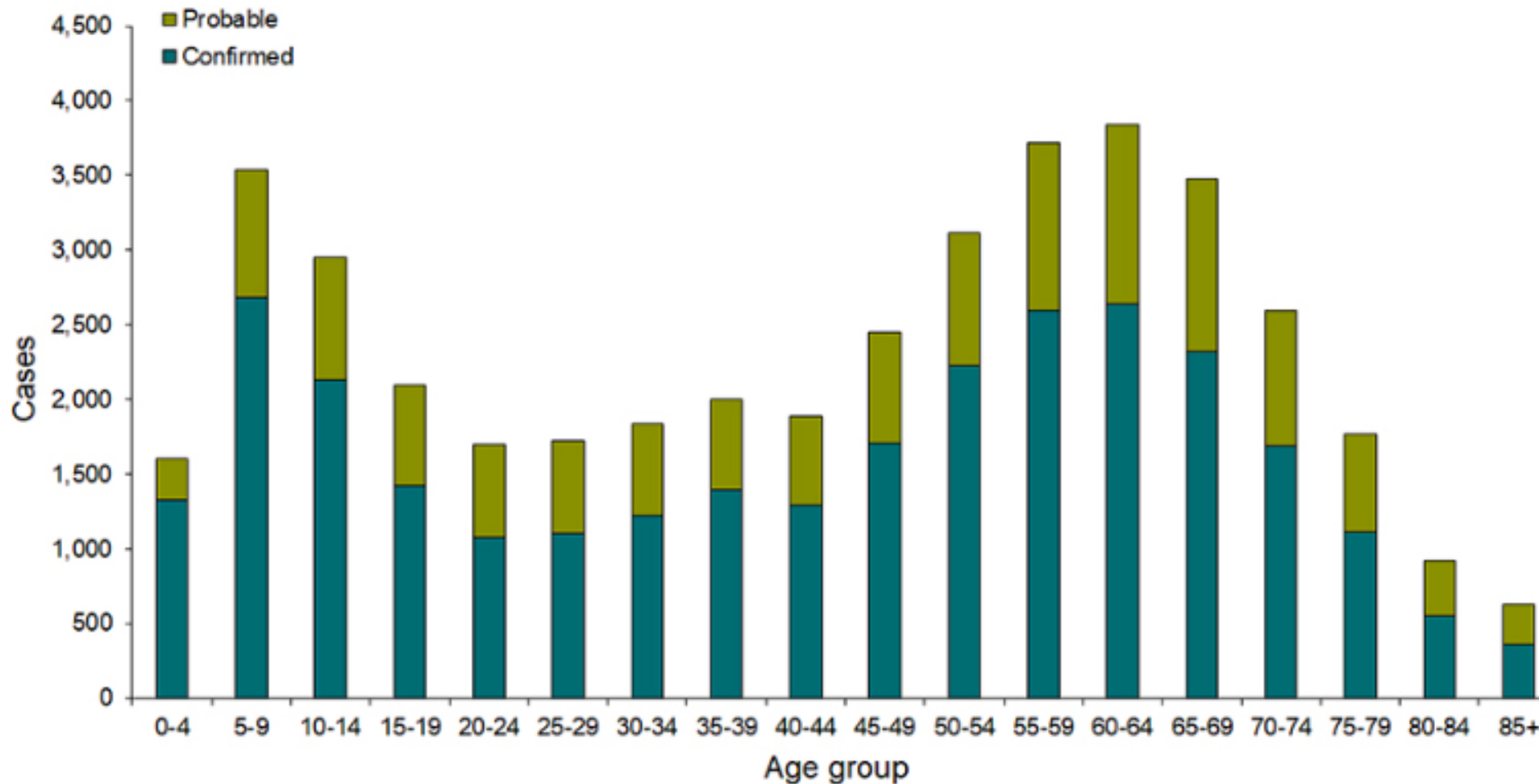
I have a new relationship with nature

So must you

# Protect, teach children



# Lyme disease—Reported cases by age group, United States, 2017





Be vigilant

Be your best advocate

**Get informed.**

**Get treated.**

# Chronic Neurologic Manifestations of Lyme Disease

Eric L. Logigian, M.D., Richard F. Kaplan, Ph.D., and Allen C. Steere, M.D.

## CONCLUSIONS.

Months to years after the initial infection with *B. burgdorferi*, patients with Lyme disease may have chronic encephalopathy, polyneuropathy, or less commonly, leukoencephalitis. These chronic neurologic abnormalities usually improve with antibiotic therapy. (N Engl J Med 1990; 323:1438–44.)

*Source: New England Journal of Medicine, 1990*

# About face

*“Now we have found a spirochete capable of spreading transplacentally to the organs of the fetus, causing congenital heart disease and possible death of the infant.”*

*Dr. Willy Burgdorfer – The Enlarging Spectrum of Tick-Borne Spirochetoses:  
R. R. Parker Memorial Address, Reviews of Infectious Diseases. Vol 8, No 6.  
November-December 1986.*