

MASSACHUSETTS LYME COALITION

# LYME ADVOCACY STARTS WITH YOU

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Project Lyme Advocacy Q&A  
October 28, 2021

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# Agenda

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- Problem & Solution
- Massachusetts as a Case Study
- Lyme Advocacy Roadmap to Success: 6 Keys
- Creating Effective Health Policy
- Inclusive Social Media Campaign: Participatory Photography
- Call to Action



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## MASSACHUSETTS LYME COALITION



Massachusetts Lyme Coalition, State House Testimony

**“NEVER UNDERESTIMATE THE  
POWER OF A SMALL GROUP OF  
COMMITTED PEOPLE TO  
CHANGE THE WORLD. IN FACT,  
IT IS THE ONLY THING THAT  
EVER HAS.”**

-MARGARET MEAD

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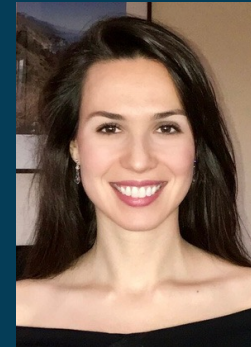
# MASSACHUSETTS LYME COALITION TEAM



**TRISH MCCLEARY**

Co-founder

A Lyme survivor, Trish served as a governor-appointed member on the Massachusetts Lyme Special Commission, co-founded Sturbridge Lyme Awareness of Massachusetts, and was awarded the Massachusetts' Unsung Heroine of 2015 for her efforts in Lyme disease advocacy.



**MICHELLE TRESELER**

Co-founder

A Lyme survivor, Michelle wrote the final version of the legislation that mandates insurance coverage for Lyme disease in Massachusetts which now serves as a model for other states. She championed the life-saving legislation and as a health policy consultant, she has worked on successful state, national and international health initiatives.

Lyme disease is the largest vector-borne disease in the US. In 2017 alone, 8,692 people tested positive for Lyme disease in MA. **Dr. Catherine Brown, state epidemiologist estimates around 87,000 people are contracting Lyme each year in MA.**



**In MA, insurers were denying coverage for Lyme disease treatment,** citing restrictive insurance guidelines. **As a result, many people with Lyme were unable to afford necessary medical treatment** and were suffering as a result.



**Created and championed a bill to require insurance companies to pay for long-term antibiotic therapy for Lyme disease, and cover experimental drug therapies for Lyme as long as the drug is approved by the FDA and indicated for off-label use for Lyme disease.**



**Catalyzed the MA Lyme community and the legislature to override a gubernatorial veto and pass our Lyme patient protection law, *An Act relative to long-term antibiotic therapy for the treatment of Lyme disease.***



# Insurance Denial of Care

S.H. - "Denied coverage for IV antibiotics by Blue Cross Blue Shield-Anthem. I saw my most progress during my 3 month treatment but had to come off of it because of denial and now cannot afford it on my own. I appealed my denial 3 times..." to no avail.

L. F. – "Insurance doesn't cover office visits and I paid for my IV antibiotics for over a year that insurance wouldn't pay. We spent over \$10,000 last year. Now my husband may need IV antibiotics and will be out of work for a month or two."

A young woman of 24 was misdiagnosed with ALS and given two years to live... Their insurance denied...IV antibiotics.. she appealed the decision... insurance company eventually agreed to the treatment, but [there was] a significant delay in getting it started. Years later, the patient is much improved, but suffered... residual effects, for which she has been awarded social security disability coverage.



**01 Identify the Problem(s)**

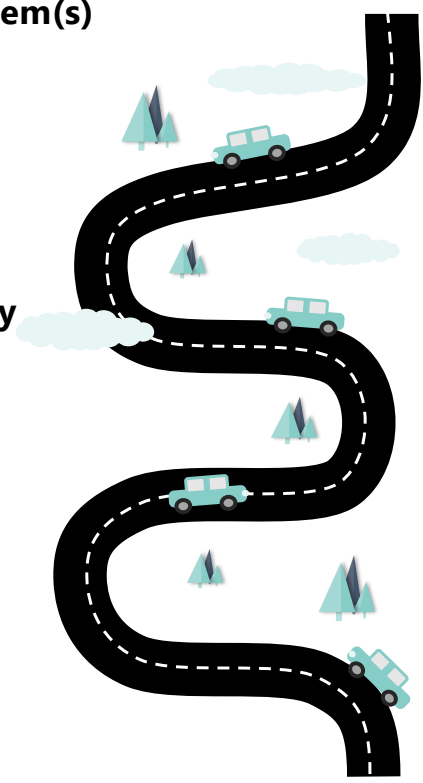
**02 Identify Policy Issue(s)**

**03 Assess Community Readiness**

**04 Identify Key Stakeholders**

**05 Engage & Empower Community**

**06 Co-create, Develop & Implement Plan of Action**



# Lyme Advocacy Roadmap to Success

6 essential steps





## (1) IDENTIFY PROBLEMS & (2) IDENTIFY POLICY ISSUES

People with Lyme disease unable to afford medical care due to health insurers' denial of Lyme disease treatment coverage



*Patient Protection bill mandating health insurance coverage for Lyme disease*

Doctors at risk of losing medical license due to Lyme treatment



*Doctor protection bill*

Lack of prevention, education or awareness efforts



*Proclamation for Lyme Disease Awareness Month*

Lack of adequate surveillance of prevalence of Lyme disease



*Increased Lyme funding and/or directive to state health department requiring Lyme disease cases are adequately counted*



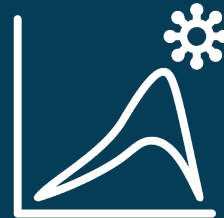
# Community Priority List



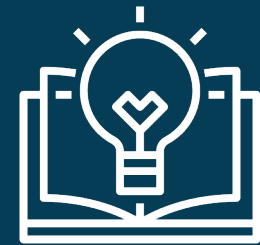
Protect Patients



Protect Doctors



Adequate Surveillance



Increase Awareness  
& Education



Increase Funding for Lyme Prevention, Early  
Intervention, Treatment and Research



Enhance Community  
Engagement



# Overview



## THE PROBLEM

- **Insurance providers denying coverage for Lyme disease treatment to MA residents, citing restrictive insurance guidelines**
- Many people unable to afford necessary medical treatment and experience loss of quality of life, wages, and education
- Huge productivity loss and lost economic output to the state



## THE SOLUTION

- **Create legislation that mandates Lyme disease insurance coverage**
- Lead a community-based grassroots movement
- Engage and empower people to communicate directly with their policymakers



## WHY WE WON

- **Years of consistent effort to proactively guide the bill through the legislative process**
- Multi-faceted effort: increase awareness, engage the media, write cost-analysis reports, etc.
- Ability to quickly mobilize the community to take immediate action



## (3) Assess Community Readiness

- Assess capacity & resources
- Is your Lyme community ready to actively engage in working towards this goal?
- If the answer is no, then would other strategies help prepare the community, such as enhancing education and increasing awareness?
- Review ideas with interested community members



## (3a) Evaluate Current Conditions

- Carefully evaluate what has been done so far
- What is the history of advocacy efforts in your state?
- Has it been tried already? What happened? Why?
- Start to look for the opposition. Are proponents of the bill actually trying to get it passed or not? Who might not want it to pass?
- A good place to start with policy creation is: Do you have a legally sound, effective bill? If not, is there another state that has passed a similar bill and been successful?
- Is the community engaged and unified?

## Our Law At-a-Glance: Details Matter

What you don't see in the bill is crucial:

### Important change:

And vs. or

### Defined terms:

The word "chronic" has been removed.

Added the term "licensed" in front of physician, which is what is found in the Physician Protection Law, and I took out the reference to the definition of physician as is found in the Massachusetts General Law as simply could be read as only referring to Massachusetts physicians. We did not want to inadvertently limit insurance coverage (as many people's insurance coverage covers seeing physicians in other states) or people's choice of physicians strictly to those practicing in Massachusetts, as many Massachusetts residents have to go to NY or CT or RI to see a physician who will treat Lyme disease.

The language was not consistent in the bill. It said "long-term antibiotic therapy" and then "long-term antibiotic treatment." The problem is that long-term antibiotic therapy is defined, and long-term antibiotic treatment is not.

## *An Act relative to long-term antibiotic therapy for the treatment of Lyme disease*

***Whereas, The deferred operation of this act would tend to defeat its purpose, which is to provide for long-term antibiotic therapy for the treatment of Lyme disease, therefore it is hereby declared to be an emergency law, necessary for the immediate preservation of the public convenience.***

*Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:*

Section 47HH. (a) For the purposes of this section, "Lyme disease" and "Long-term antibiotic therapy" shall have the same meaning as ascribed to them in section 12DD of chapter 112.

(b) A policy, contract, agreement, plan or certificate of insurance issued, delivered or renewed within the commonwealth that provides medical expense coverage shall provide coverage for long-term antibiotic therapy for a patient with Lyme disease when determined to be medically necessary and ordered by a licensed physician after making a thorough evaluation of **the patient's symptoms, diagnostic test results, or response to treatment. An experimental drug shall be covered as a long-term antibiotic therapy if it is approved for any indication by the United States Food and Drug Administration; provided, however, that a drug, including an experimental drug, shall be covered for an off-label use in the treatment of Lyme disease if the drug has been approved by the United States Food and Drug Administration.**



# Rhode Island (2003)

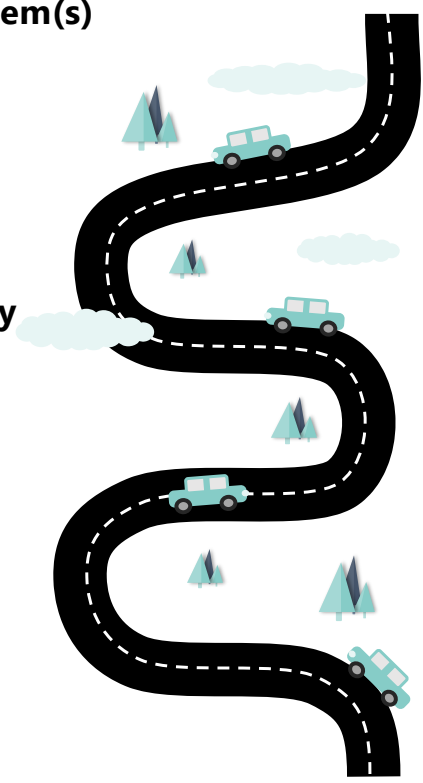
“shall provide coverage for diagnostic testing and long-term antibiotic treatment of **chronic lyme disease** when determined to be medically necessary and ordered by a physician acting in accordance with chapter 5-37.5 of the Rhode Island General Laws entitled "lyme disease diagnosis and treatment" after making a thorough evaluation of the patient's symptoms, diagnostic test results **and** response to treatment.”



**01 Identify the Problem(s)**

**03 Assess Community Readiness**

**05 Engage & Empower Community**



**02 Identify Policy Issue(s)**

**04 Identify Key Stakeholders**

**06 Co-create, Develop & Implement Plan of Action**

# Lyme Advocacy Roadmap to Success

6 essential steps





## (4) Identify Key Stakeholders



### POTENTIAL ALLIES

- Legislative Champions
- Potential Co-sponsors of the legislation
- Active members of the community
- Unions & Associations
- YOU!



### POTENTIAL OPPONENTS

- Insurance Industry
- Governor
- Legislators
- Unknown



# Legislative Champions



Senator Anne Gobi



Representative David Linsky

"People over politics. Results over Rhetoric." – Senator Gobi

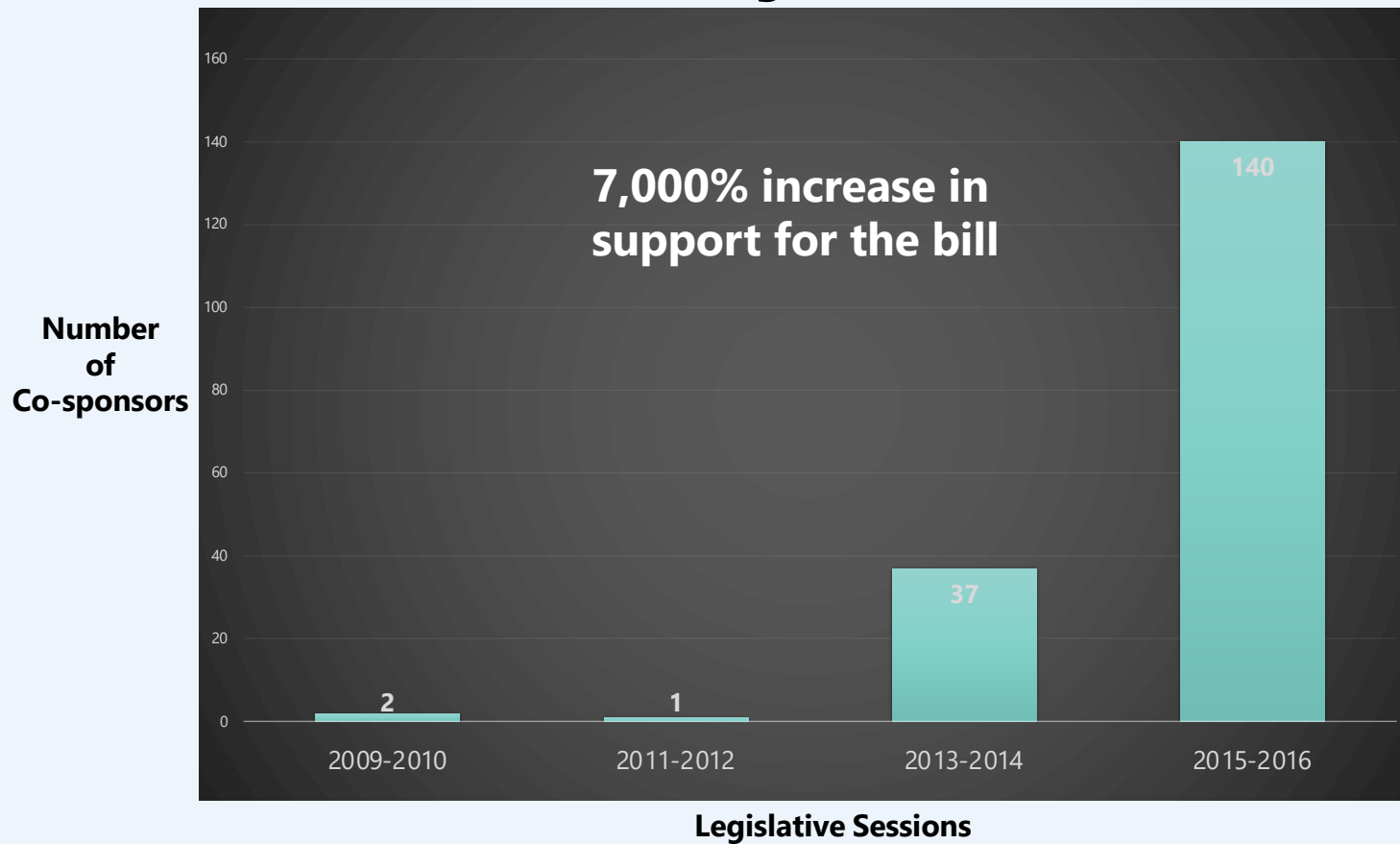


## (5) Engage and Empower Community

- Engage and empower community to take action
- Send out calls to action: scripted e-mails, letters, etc.
- Create social media campaigns
- Effectively advocate for health policy by conducting community, press and legislative outreach through editorials, briefings, press releases and interviews.
- Educate members of the public, state officials, legislators and the press regarding public health policy through testimony, meetings and multi-media outreach.



# Legislative Co-sponsors of MA Lyme Bill



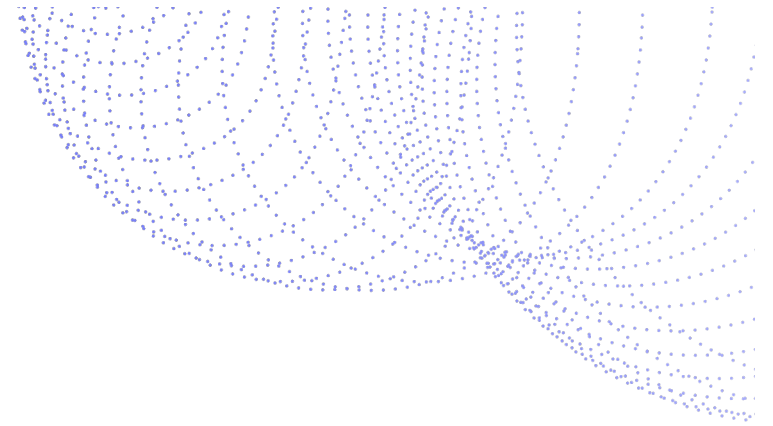


**70%**

MA LEGISLATORS SIGNED ON AS CO-SPONSORS



# Legislative Timeline



2009-2012

Bill proposed twice

- Contained flaws that would have harmed the community if it had passed
- 2 co-sponsors in 2009-2010
- 1 co-sponsor in 2011-2012

2/2013

MA Special Commission

- McCleary serves on commission that recommends "mandatory Lyme disease insurance coverage to be enacted in Massachusetts."

2013

Created a new version of the bill

- Treseler joined the fight and re-wrote the bill, created legislative brief, conducted outreach to legislators, and testified in support of a revised bill

2013

Sponsoring legislator

- Refuses to incorporate necessary changes
- Met with insurance lobbyists shortly before bill was set to be voted on
- "Bad" bill died in committee

2013

Find a new champion legislator

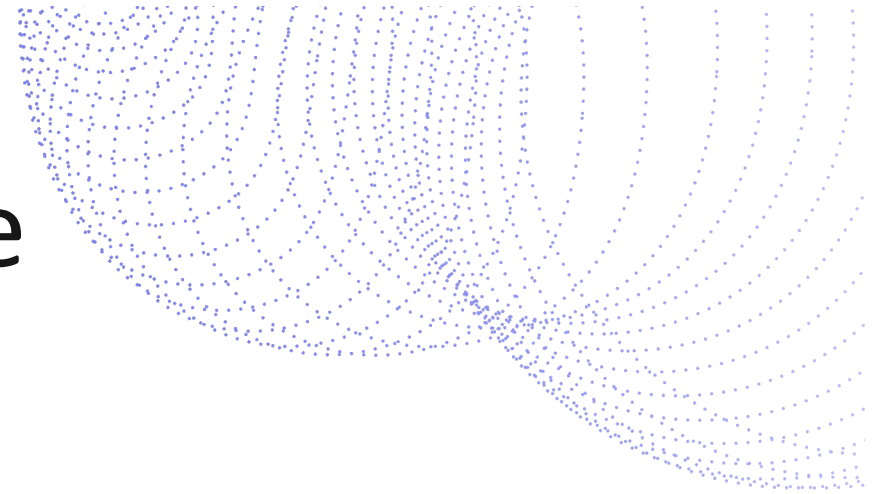
2013-14

MA Lyme Coalition created

- Join forces for legislative advocacy



# Legislative Timeline



2013-14

Increase support for the bill

- CHIA report

1/2015

Our clean version of the bill is proposed

- Secure 140 co-sponsors

1/2015- 4/2016

Bill in Joint Committee on Financial Services

- Testified at hearing 10/15

4/2016

Bill in Committee on Healthcare Financing

- Join forces for legislative advocacy

5/2016

Bill goes to House and Senate

5-7/2016

Bill approved by House and Senate



## **(5a) Create Clear Communication Channels & Identify Shared Values**

- What are your channels of communication?
  - E-mail listserv
  - Facebook page
  - Twitter Account
  - E-mail and letter campaigns
  - Social media campaigns
- What are your shared values?
  - Openness, transparency, trust, honesty, etc.







# Social Media Campaign

- 1 Developed and led a participatory photography campaign
- 2 Empowered citizens with disabilities to communicate directly with policymakers to increase participation in legislative advocacy
- 3 Legislators saw constituents who would be positively impacted by passage of the bill.





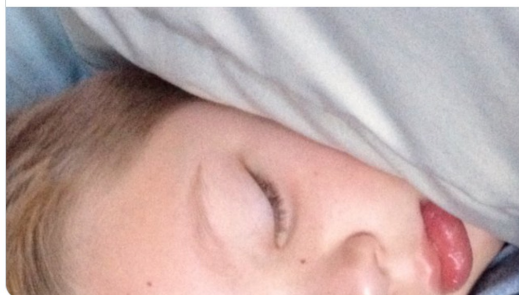
**MA Lyme Coalition** @LymeCoalition · Jul 1, 2016 ...  
 Andrea and her kids need your support @MassGovernor to afford access to care for #LymeDisease #maleg #mapoli

**MA Lyme Coalition** @LymeCoalition · Mar 2, 2016  
 Please help Andrea & 2 kids beat #Lyme & #Pass502in2016 @jeffroy @SenRichardJRoss @JamieEldridgeMA @RepMichlewitz



**MA Lyme Coalition** @LymeCoalition · Jul 1, 2016 ...  
 Sean from Bolton needs your support @MassGovernor #LymeDisease is here to stay.

**MA Lyme Coalition** @LymeCoalition · Mar 2, 2016  
 Please help Sean from Bolton beat #Lyme & #Pass502in2016 @repkatehogan @JenFlanaganMA @MassGovernor #Kids1stMA



**MA Lyme Coalition** @LymeCoalition · Jul 1, 2016 ...  
 Trish from Sturbridge asks for your continued support @MassGovernor #LymeDisease nearly took her life #maleg #mapoli

**MA Lyme Coalition** @LymeCoalition · Mar 2, 2016  
 Please help Trish from Sturbridge beat #Lyme & #Pass502in2016 @AnneGobi @ToddSmola @RepMichlewitz @JamieEldridgeMA



**MA Lyme Coalition** @LymeCoalition · Jul 1, 2016 ...  
 Deb from Uxbridge is counting on you @MassGovernor #LymeDisease #maleg #mapoli

**MA Lyme Coalition** @LymeCoalition · Mar 2, 2016  
 Please help Deb from Uxbridge beat #Lyme & #Pass502in2016 @KevinKuros @RyanFattman @RepMichlewitz @JamieEldridgeMA



**MA Lyme Coalition** @LymeCoalition · Jul 1, 2016 ...  
 Erin maintains a smile as she fights #LymeDisease @MassGovernor #maleg #mapoli

**MA Lyme Coalition** @LymeCoalition · Feb 29, 2016  
 #MassMillenials need you! Please #Pass502in2016 and help Erin beat #Lyme @RyanFattman @EricLesser @SenStan #mapoli



**MA Lyme Coalition** @LymeCoalition · Jul 31, 2016 ...  
 Your constituents are counting on you to help #PassLymeBill. Let's #OverrideLymeVeto. @JamieEldridgeMA @EricLesser

**MA Lyme Coalition** @LymeCoalition · Feb 24, 2016  
 Please help Gene from Warren beat #Lyme & #Pass502in2016 @AnneGobi @JamieEldridgeMA @EricLesser #mapoli





# Recommendation

Participatory photography  
social media campaign



# (6) Co-create, Develop and Implement Plan of Action

- ✓ Identified the problem(s)
- ✓ Identified the policy issue
- ✓ Assessed Community Readiness
- ✓ Identified Key Stakeholders
- ✓ Engage and Empower Community

- Create effective health policy
- Develop 1 page legislative brief
- Work with community members and reach out to legislators
- Take efforts to increase Lyme and tick-borne disease education, raise awareness and encourage patient advocacy
- Engage and empower citizens with Lyme to communicate directly with their policymakers through a social media campaign
- Steps to proactively guide the bill through the legislative process
- Galvanize the community to attend and share testimony at hearings
- Cost-benefit analysis reports
- Meet regularly with group of advocates
- Conduct community, press and legislative outreach through editorials, briefings, press releases and interviews.
- Offer Scripted Calls to Action – Make it Easy for People to Participate



# Massachusetts in the bulls-eye; Proposed Lyme Disease Measure could save lives



Vi

Town News

## Local advocates work to improve care for Lyme disease patients

LOCAL NEWS

### Battle rages over Lyme disease bill

### Four Turn: Life-saving legislation on Beacon Hill

## Massachusetts face to face with Lyme disease patient protection bill



isease are applauding / for physician- ients.

a prescription for

: Gov. Charlie Baker's minutes to spare

before the current legislative session ended at midnight  
Sund: the M

be's Misrepresentation of Lyme Disease

016 · 5 min read



epicenter of Lyme disease, an infectious disease that nes more common than HIV/AIDS. The Boston orial regarding pending Lyme disease legislation on

## Lyme Bill at the Finish Line

Michelle Treseler Jul 19, 2016 · 4 min read



Baker insura infectious disease specialists, immunologists and

Opinion

## McCleary: State faces a Lyme crisis





# Massachusetts Center for Health and Information Analysis

## What is the cost of implementing the bill?

- According to the 2014 MA Center for Health and Information Analysis report, requiring coverage for this benefit by fully-insured health plans would result in an average annual increase, over five years, to the typical member's monthly health insurance premiums of **between a negligible amount (0.00%) and \$0.13 (0.02%) per year.**

## What is the cost of not implementing the bill?

- According to David P. Linsky, Chair of the House Committee on Post Audit and Oversight, "**millions of dollars are lost in employee absences due to Lyme disease.** Each year, hundreds of school children miss school. Millions of dollars are spent in medical care."
- In the MA Lyme Commission Report (2013), it notes that **chronic illness accounts for 84% of Lyme healthcare costs. Only 21% of this figure is due to the cost of treatment, while 79% is due to lost economic output or productivity loss.**



# Massachusetts Lyme Legislation Timeline



**7/11/2016**

Governor  
returned to  
House with  
amendments

**7/14/2016**

Governor  
amendments  
rejected

**7/18/2016**

Emergency  
Preamble  
adopted

**7/28/2016**

Governor  
Vetoes our  
Bill

**7/30-31/2016**

**IT'S  
OFFICALLY  
LAW!**  
HOUSE & SENATE  
OVERRIDES VETO





# Build Momentum State by State



# West Virginia

**West Virginia, Senate Bill 242**

**Signed into law: March 20, 2018**

**Effective June 6, 2018**

...shall provide coverage for long-term antibiotic therapy for a patient with Lyme disease when determined to be medically necessary and ordered by a licensed physician after making a thorough evaluation of the patient's symptoms, diagnostic test results, or response to treatment.

# Massachusetts

**Massachusetts, House Bill 4491**

**Signed into law: July 31, 2016**

**Effective July 31, 2016**

...shall provide coverage for long-term antibiotic therapy for a patient with Lyme disease when determined to be medically necessary and ordered by a licensed physician after making a thorough evaluation of the patient's symptoms, diagnostic test results, or response to treatment.



**“STATE SENATOR CHARLES TRUMP IS  
USING THE MASSACHUSETTS  
LEGISLATION AS A GUIDE  
TO FORCE INSURANCE COMPANIES TO  
PAY FOR THE EXTENDED THERAPY  
NEEDED BY WEST VIRGINIA CHRONIC  
LYME VICTIMS.”**

**CHRONIC LYME EFFORT PROGRESSES  
BY MARY HEATH  
JANUARY 20, 2018  
IN THE JOURNAL**

# Illinois

**Effective January 1, 2020**

...shall provide coverage for long-term antibiotic therapy, including necessary office visits and ongoing testing, for a person with a tick-borne disease when determined to be medically necessary and ordered by a physician licensed to practice medicine in all its branches after making a thorough evaluation of the person's symptoms, diagnostic test results, or response to treatment. An experimental drug shall be covered as a long-term antibiotic therapy if it is approved for an indication by the United States Food and Drug Administration. A drug, including an experimental drug, shall be covered for an off-label use in the treatment of a tick-borne disease if the drug has been approved by the United States Food and Drug Administration.

# Massachusetts

**Effective July 31, 2016**

...shall provide coverage for long-term antibiotic therapy for a patient with Lyme disease when determined to be medically necessary and ordered by a licensed physician after making a thorough evaluation of the patient's symptoms, diagnostic test results, or response to treatment. An experimental drug shall be covered as a long-term antibiotic therapy if it is approved for an indication by the United States Food and Drug Administration; provided, however, that a drug, including an experimental drug, shall be covered for an off-label use in the treatment of Lyme disease if the drug has been approved by the United States Food and Drug Administration.





“

When the story of Lyme disease  
is written, it will be the story of  
patients standing up  
and being heard.

-Senator Richard Blumenthal





**YOUR VOICE  
MATTERS.**





# CALL TO ACTION

## WILL YOU LEAD LYME ADVOCACY EFFORTS IN YOUR STATE?

The more states that pass legislation mandating Lyme disease insurance coverage, the greater likelihood we have of mandating insurance coverage for Lyme with federal legislation.

## YOUR VOICE MATTERS

Share your story.

CONTACT YOUR  
REPRESENTATIVES AND ASK  
WHAT THEY ARE DOING  
ABOUT LYME DISEASE.



# Resources

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## MASSACHUSETTS LYME COALITION TESTIMONY

<https://bit.ly/3IK0kUw>

## MASSACHUSETTS LYME COALITION LAW

<https://malegislature.gov/Laws/SessionLaws/Acts/2016/Chapter183>

MY E-MAIL

livevechi@gmail.com







“

We need leaders not in love with money but in love with justice. Not in love with publicity but in love with humanity. –

MLK, Jr.