**Centers for Disease Control and Prevention Office of Communications** 



## New Clinical Tools and Resources to Support Patients with Prolonged Symptoms and Concerns about Lyme Disease

Clinician Outreach and Communication Activity (COCA) Call

Thursday, September 19, 2024

### **Free Continuing Education**

- Free continuing education is offered for this webinar.
- Instructions for how to earn continuing education will be provided at the end of the call.

### **Continuing Education Disclosure**

- In compliance with continuing education requirements, all planners, presenters, and moderators must disclose all financial relationships, in any amount, with ineligible companies over the previous 24 months as well as any use of unlabeled product(s) or products under investigational use.
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- Content will not include any discussion of the unlabeled use of a product or a product under investigational use.
- CDC did not accept financial or in-kind support from ineligible companies for this continuing education.

### **Objectives**

At the conclusion of today's session, the participant will be able to accomplish the following:

- 1. Describe the epidemiology and clinical presentation of Lyme disease.
- 2. Describe what is known about acute and prolonged symptoms associated with Lyme disease.
- 3. Outline clinical approaches, tools, and resources for healthcare providers caring for patients with prolonged symptoms and concerns about Lyme disease.

### **To Ask a Question**

- Using the Zoom Webinar System
  - Click on the "Q&A" button
  - Type your question in the "Q&A" box
  - Submit your question
- If you are a patient, please refer your question to your healthcare provider.
- If you are a member of the media, please direct your questions to CDC Media Relations at 404-639-3286 or email <u>media@cdc.gov</u>.

### **Today's Presenters**

Erica Kaufman West, MD, FACP, FIDSA
 Director of Infectious Diseases
 American Medical Association

 Grace Marx, MD, MPH, FIDSA CDR, U.S. Public Health Service Medical Officer, Bacterial Diseases Branch Division of Vector-Borne Diseases Centers for Disease Control and Prevention Helping Clinicians Care for Patients with Prolonged Symptoms and Concerns about Lyme Disease

> Erica Kaufman West, MD, FACP, FIDSA Director of Infectious Diseases American Medical Association

## **AMA-CDC Collaboration**

- The AMA recognizes that:
  - Vector-borne diseases are an increasing public health threat
  - There is confusing and contradictory information related to the diagnosis and treatment of Lyme disease
  - There is a need for education on infection-associated chronic illnesses
- Project funded through Cooperative Agreement (CK20-2003): 2021-2024
- Goal: Improve care for patients with prolonged symptoms and concerns about Lyme disease

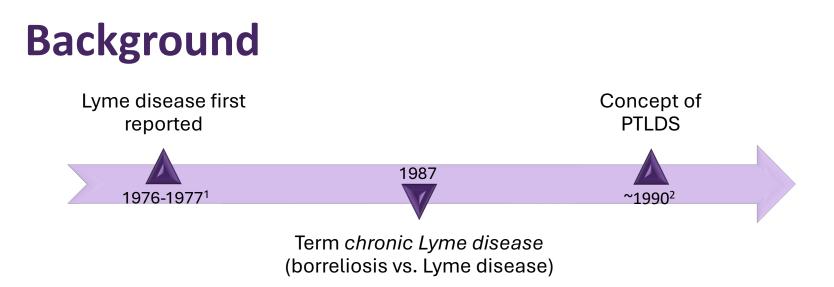


## Lyme disease

- Caused by infection with Borrelia burgdorferi.
- Vector is the *Ixodes* blacklegged tick.
- Three initial phases of disease
  - Early localized disease: erythema migrans rash
  - Early disseminated disease: cranial neuritis, heart block
  - Late disseminated disease: monoarticular arthritis
- Early diagnosis and treatment is important to prevent disseminated disease.
- Treatable with 10 days 4 weeks of antibiotics, depending on clinical manifestation.

## **Post-Treatment Lyme Disease Syndrome**

- PTLDS is a condition characterized by fatigue, joint and muscle pain, and difficulty concentrating.
- Prospective studies show that at 6 months after treatment for Lyme disease, 5 10% more patients have these symptoms compared to population controls.
- The cause is unknown.
- If a patient has been treated for Lyme disease with antibiotics and has prolonged symptoms, multiple studies have shown that more antibiotics do not provide lasting improvement in symptoms.



"The controversy around chronic Lyme disease emerged when patient advocacy groups and some doctors began to use the term to describe patients who had nonspecific symptoms such as fatigue and pain, and testing did not always show that they had been exposed to Lyme disease."

#### – John Aucott, MD<sup>3</sup>

Steere AC, Broderick TF, Malawista SE. Erythema chronicum migrans and Lyme arthritis: epidemiologic evidence for a tick vector. Am J Epidemiol. 1978 Oct;108(4):312-21. doi: 10.1093/oxfordjournals.aje.a112625. PMID: 727200.
 Robert B. Nadelman, Steven W. Luger, Elliot Frank, et al. Comparison of Cefuroxime Axetil and Doxycycline in the Treatment of Early Lyme Disease. Ann Intern Med.1992;117:273-280. doi:10.7326/0003-4819-117-4-273
 Aucott JN. Chronic Lyme Disease – Does it Exist? The Conversation. 5.21.2020

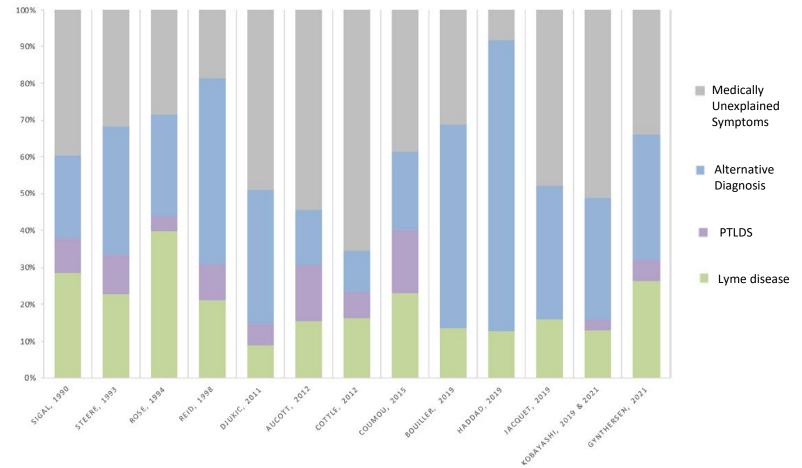
## Background (continued)

- Hundreds of thousands of patients suffering from medically unexplained symptoms.
- Patients and physicians have a hard time with medically unexplained symptoms.
- Some patients may wonder if their symptoms are due to Lyme disease.
- Biomedical model of medical education
  - Necessary
  - Places high value on diagnosing disease
- Failure of a diagnosis is not the failure of the physician or of the patient it is simply a failure of current medical knowledge

## Background (continued 2)

- US health care system is challenging for these patients.
  - Insurance reimbursement
  - In- vs. out-of-network
  - Limited availability of some specialists
  - Lack of knowledge about Lyme disease and Infection-Associated Chronic Illnesses
  - Misinformation online
- Can lead to "medical wandering"

### Lyme disease accounts for minority of patients referred for CLD



Marques A. Persistent Symptoms After Treatment of Lyme Disease. *Infect Dis Clin North Am.* 2022 Sep;36(3):621-638.

### Unexplained post-acute infection syndromes (PAIS)

Jan Choutka <sup>1</sup><sup>1</sup><sup>2</sup>. Virai Jansari<sup>2</sup>. Madv Hornig<sup>3</sup> and Akiko Iwasaki<sup>2,4,5,6</sup>

Pathogen	Name of PAIS			
/iral pathogens				
	Post-acute sequelae of SARS-CoV-2 infection (PASC)			
SARS-CoV-2	Post-acute COVID-19 syndrome (PACS)			
	Long COVID			
<b>Eholo</b>	Post-Ebola syndrome (PES)	a		
Ebola	Post-Ebola virus disease syndrome (PEVDS)	Ł		
Dengue	Post-dengue fatigue syndrome (PDFS)			
Polio	Post-polio syndrome (PPS)	6		
SARS	Post-SARS syndrome (PSS)	me (PSS) dS		
	Post-chikungunya chronic inflammatory			
Chikungunya	rheumatism (pCHIK-CIR)			
	Post-chikungunya disease			
EBV	No name			
West Nile virus	No name			
Ross River virus <sup>a</sup>	No name			
Coxsackie B <sup>a</sup>	No name			
H1N1/09 influenza <sup>a,b</sup>	No name			
VZV <sup>a,b</sup>	No name			

Pathogen	Name of PAIS				
Non-viral pathogens					
Coxiella burnetii	O fever fatigue syndrome (OFS)				
Borrelia <sup>c</sup>	Post-treatment Lyme disease syndrome (PTLDS)				
Giardia lamblia <sup>a,d</sup>	No name				
<sup>a</sup> Limited or very limited evidence base.					
<sup>b</sup> Association with increased use of ME/CFS diagnosis in health					
registry.					
<sup>c</sup> Contradicting or unclear evidence base.					
<sup>d</sup> Supporting evidence derives from a single outbreak in Norway.					

### PTLDS, PAIS/IACI: Same etiopathogenesis?

- Natural variation in resolution times
- Autoimmunity / immune dysregulation
- Persistent infection
- Response to retained antigen
- Intercurrent conditions
- Anchoring bias



### Self-knowledge Check

Which of the following statements are true regarding Post Treatment Lyme Disease Syndrome (PTLDS)?

- A. It affects about 5-10% of people diagnosed and treated for Lyme disease.
- B. Common symptoms include fatigue, body aches, and difficulty concentrating.

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- **C.** It is best treated with prolonged courses of antibiotics.
- D. A and B only
- E. All of the above

### Self-knowledge Check

The correct answer is: D.

Rationale: Multiple studies have shown that after treatment for Lyme disease, about 5-10% of people will have prolonged symptoms, lasting 6 months or more. The main symptoms reported are fatigue, joint and muscle pains, and difficulty concentrating. While the pathophysiology is unknown, multiple studies looking at long-term antibiotics vs placebo have not shown a lasting benefit.



AMA-CDC Project Aims and Methods

- Identify possible needs
  - Conduct literature review, learn landscape
- Gather physician insights
  - Focus groups and in-depth interviews
  - Conference presentations and discussions
- Develop materials, target, and train
  - Resources for clinicians and patients
  - Dissemination and evaluation



Project Aims and Methods

- Identify possible needs
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## Focus groups and in-depth interviews

- **Objective:** To understand how physicians manage patients presenting with persistent/prolonged symptoms and concerns about Lyme disease to help improve care for these patients.
- Methods: Four 30-minute interviews and four 1-hour focus groups in June and July 2022, including 25 experienced physicians



## **Inclusion criteria**

- **Specialties**: primary care, infectious diseases, neurology, psychiatry, and rheumatology
- Participants attested that they did not only focus on Lyme disease, they:
  - Treated a wide range of conditions in their specialty
  - Typically saw 5-30 patients per year who were referred for chronic Lyme disease
  - Were not a resident or fellow



## **Three clear themes**

 Need to validate patient symptoms, make patients feel heard I need to listen holistically...people feel like they've been listened to...the best experiences that we have had with the patients...is when we listen...they are more likely to listen to and believe you.

 These visits take a lot of time and can be overwhelming

I spend a ton of time in my Lyme visits...

 High overlap with fibromyalgia, chronic fatigue syndrome, Long COVID

"I am so tired and fatigued," is it COVID? Is it Lyme disease?

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Developing Physician Resources



Presentation and discussion at the AMA Interim Meeting, November 2022

Media story on AMA website highlighting Interim Meeting session



Online educational module with CME



AMA website with toolkit



Manuscript, editorial: under development

## Module

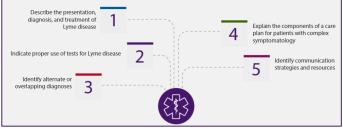


- Free CME
- Focus on patients with prolonged symptoms
  - How to welcome patients
  - Importance of a differential diagnosis
  - Utilizing a multidisciplinary approach
  - Building an individualized care plan
- Lyme disease overview

Caring for Patients with Prolonged Symptoms and Concerns about Lyme Disease. Ary point you may tick it/et/pto review this Curser navigation elements. When you're ready to get started, click Next

#### Learning Objectives

Caring for Patients with Prolonged Symptoms and Concerns about Lyme Disease After completing this module, you will be able to:



• **Goal**: educate clinicians on how to provide better care for patients whether we understand the cause of their symptoms or not.

## Toolkit

- CME module
- Videos
- Supplemental handouts
- Tips on motivational interviewing



#### How to use this toolkit

This toolkit can help physicians and other health care professionals provide better care for patients with prolonged symptoms and concerns about Lyme disease. The toolkit gathers:

- Best practices and guidance from CDC, medical professional societies including American Academy of Neurology (AAN), American Academy of Physical Medicine and Rehabilitation (AAPM&R), American College of Rheumatology (ACR), Infectious Diseases Society of America (IDSA) and practicing clinicians
- $\bullet\,$  Resources for patients and health care professionals
- $\bullet~$  Interviews with experts
- A <u>CME module</u>
- $\bullet\,$  Video examples of health care professionals who care for complex patients
- Tips on how to provide comprehensive and empathetic care

Explore the steps below to learn more.









Welcoming patients

Evaluating diagnoses

Compiling a team

Developing a care plan

AMA

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## Videos

- Interviews with experts
  - Camille Kroll, MPH
  - Paul Auwaerter, MD, MBA
- Recorded webinar with CDC

### **Interviews with experts**



Camille Kroll, MA, MPH, CHP



Paul Auwaerter, MD, MBA



### **Example Handouts for Patients**

#### **Symptom Diary**

It's important to track your symptoms and how they vary from day to day. Writing them down and sharing them with your physician and others on your care team can help determine triggers to your symptoms and how you are responding to interventions.

Below is an example of how you can keep track of your symptoms and their severity over time.

#### Symptoms

Fatigue (F), Headache (H), Shortness of Breath (S)

#### Severity

Mild (1-5), Severe (6-10)

#### Symptom Diary

Date	Day	Severity	Symptoms
5/1	Sunday	9	(F) Walked to the corner and back, extreme fatigue at 6p
5/2	Monday	10	(F) Couldn't get out of bed all day
5/3	Tuesday	6	(F) Able to do some laundry, napped at 2p
5/4	Wednesday	5	(F) Friend brought lunch over, sat outside for a few hours
5/5	Thursday	8	(H) Headache, tried new med with no relief
5/6	Friday	4	(H) Headache, tried meditation and ibuprofen with 50% improvement
5/7	Saturday	2	(F) Better day, walk to mailbox and back, no increase in fatigue





#### **Goal Tracker**

It can be helpful to write down your health goals and list steps you can take to achieve those goals. If this worksheet doesn't fit all of your needs, feel free to create your own and share it with your clinician! Below is an example.

#### Health Goal

### Action Steps 3. Anticipated Benefits Anticipated Challenges 1. 2. 3. Lessons Learned

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### **Example Handouts for Clinicians**





#### Motivational Interviewing SAMPLE SCRIPT

It can be challenging to navigate conversations when there's a difference of opinion. For patients with prolonged symptoms who desire long-term antibiotics or other interventions that may be harmful, it can be hard to know how best to explain why they are not recommended while maintaining a positive clinician-patient relationship. Here are some examples of what you might say when a patient is seeking a treatment that is not medically indicated.



Validate their feelings. "I can understand why you feel that way."

#### Encourage discussion about harmful outcomes.

"What side effects have you experienced in the past? What problems do you think more antibiotics might cause?"

Concisely state your stance on the treatment in question, in dear terms the patient can understand.

"Multiple studies have shown there is not a benefit to taking antibiotics for a long time. Many people have experienced real harms, like blood stream infections from IV lines. I don't want you or any of my patients to experience something like that."

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### Open the door for alternative therapies.

"Besides antibiotics, what has worked for you? What else are you interested in trying?" or "I think antibiotics are too risky, but I do want to help you feel better. What other options do you think might help?"







#### **Managing Differences of Opinion**

Conflicting opinions between patients and physicians happen. These types of interactions can help foster a positive relationship or can lead to a rift between the parties, eroding the trust and confidence that both require. Learning how to manage some of the more common conflict points can help de-escalate or even avoid high tension in the office and allow you to *provide better patient care*.

### Patients who want to be tested for a particular disease:



Patient: "I want you to test me for [disease X]." or "Can you order [test X]?"

Physician: "What makes you concerned about [disease X]?" or "How do you think [test X] would be helpful?"

### Patients who want antibiotics when they are not medically indicated:



Patient: "The antibiotics are the only things that work. I need to continue taking them or I'll find another doctor."

Physician: "In what way do the antibiotics help? What improvements have you seen?" Then, "What if we try [x] for the next 2 weeks instead of the antibiotics? You can use a symptom diary to document your days, and then come back and talk about how you've been feeling. Do you think that's enough time?"

#### Helping patients manage expectations:

Physician: "We've ruled out [list conditions that have been tested for], so that's reassuring. I appreciate you bringing back the Symptom Diary, and I see you've had some good and bad days. I know there will continue to be some bad days, but what do you think is the next step to try and get more good days?"

"I know you've tried a lot of different medications for your brain fog. We've had some success, but I hear you that you're still suffering. How do you feel about seeing a neurologist, to see if there's anything we've missed or a treatment that I don't know about?

I want you to be aware that even specialists can struggle to find the right combination of therapies, so try not to be disappointed if they don't have answers right away."

Our knowledge about Infection-Associated Chronic Illness (IACI) is incomplete. It is important to remind patients that research is ongoing, and we may need to adjust our care plans as we learn more.

## Collaborations

- Received feedback from a diverse group of clinicians
- Working with other professional organizations for broad dissemination of toolkit



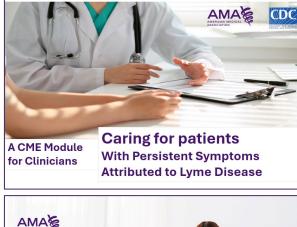
Chronic Symptoms Following Infections

#### About Chronic Symptoms Following Infections

#### KEY POINTS

- Infections can sometimes leave people with symptoms that last for weeks to months or longer, even after appropriate treatment.
- Symptoms can follow many different types of infections.
- It is important to discuss your symptoms and concerns with your doctor to develop a
  personalized treatment or care plan.









### Caring for Patients with Prolonged Symptoms and Concerns about Lyme Disease

### CDR Grace Marx, MD, MPH, FIDSA

Bacterial Diseases Branch Division of Vector-Borne Diseases Centers for Disease Control and Prevention

## **Clinical approach**

- Thoroughly explore timeline of patient's symptoms and response to any prior treatments
- Conduct a comprehensive physical exam
- Systematically consider a tailored, broad differential diagnosis
- Discuss patient's specific concerns about Lyme disease
  - Opportunity for education
  - Consider two-step serologic testing
  - Consider treatment for Lyme disease
- Build a multi-disciplinary team, coordinated by the primary care clinician

## **Consider a broad differential diagnosis**

- Autoimmune conditions
- Endocrine conditions
- Mental health conditions
- ME/CFS
- Oncologic conditions
- Post-acute infectious disease syndromes (e.g., PTLDS, long COVID)
- Sleep disorders

## Address patient's concerns about Lyme disease

- A solid clinical understanding of Lyme disease is critical
- Clinical resources
  - CDC's clinician educational series
  - NAPNAPKnowsLyme.org
  - AAN/ACR/IDSA 2020 Guidelines

#### AAN/ACR/IDSA 2020 Guidelines for the Prevention, Diagnosis and Treatment of Lyme Disease

#### Published CID, 11/30/2020

Clinical Infectious Diseases, Volume 72, Issue 1, 1 January 2021, Pages e1-e48, https://doi.org/10.1093/cid/ciaa1215 [2]

#### Published (online): 30 November 2020

Paul M Lantos, Jeffrey Rumbaugh, Linda K Bockenstedt, Yngve T Falck-Ytter, Maria E Aguero-Rosenfeld, Paul G Auwaerter, Kelly Baldwin, Raveendhara R Bannuru, Kiran K Belani, William R Bowie, John A Branda, David B Clifford, Francis J DiMario, Jr, John J Halperin, Peter J Krause, Valery Lavergne, Matthew H Liang, H Cody Meissner, Lise E Nigrovic, James (Jay) J Nocton, Mikala C Osani, Amy A Pruit, Jane Rips, Lynda E Rosenfeld, Margot L Savoy, Sunil K Sood, Allen C Steere, Franc Strle, Robert Sundel, Jean Tsao, Elizaveta E Vaysbrot, Gary P Wormser, Lawrence S Zemel

A summary guideline for clinicians may be found here.

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Introduction

Recommendations (Abridged)

## **Careful consideration of testing for Lyme disease**

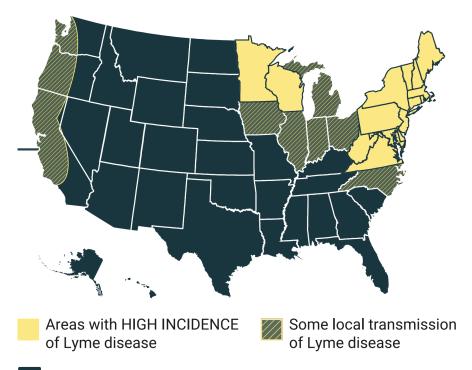
- Two-step serologic assays are the only FDA-cleared test
- Sensitivity can be low in early disease, but is high after the first 4 weeks from illness onset
- Can remain positive for years despite effective treatment
- Cross-reactivity can occur to other pathogens
- Some laboratories offer their own tests for Lyme disease that have not been FDA-cleared and whose clinical validity is unknown
- The Association of Public Health Laboratories (APHL) provides guidance on interpretation of serologic test results



Scan for APHL's Lyme disease serologic test interpretation

# What is the patient's pretest probability of Lyme disease?

1. Has the patient been in an area where Lyme disease is common?



Areas with low or no local transmission of Lyme disease

# What is the patient's pretest probability of Lyme disease? (continued)

1. Has the patient been in an area where Lyme disease is common?

2. Was the patient likely exposed to ticks?



# What is the patient's pretest probability of Lyme disease? (continued)

1. Has the patient been in an area where Lyme disease is common?

2. Was the patient likely exposed to ticks?



Scan for CDC's tick bite data tracker

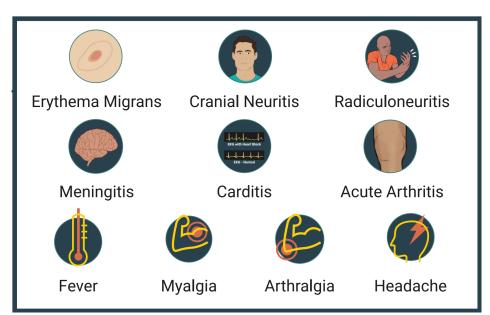


# What is the patient's pretest probability of Lyme disease? (continued 2)

1. Has the patient been in an area where Lyme disease is common?

2. Was the patient likely exposed to ticks?

3. Does the patient have symptoms characteristic of Lyme disease?



### Self-knowledge Check

What are patient characteristics that contribute to their pre-test probability of having Lyme disease?

- A. Spending time in a geographic area where Lyme disease is common
- B. Spending time outdoors in tick habitat
- C. Having symptoms characteristic of Lyme disease
- D. Having concerns about Lyme disease
- E. A, B, and C only
- F. All of the above

### Self-knowledge Check

The correct answer is E.

Rationale: Patients are more likely to have Lyme disease if they have spent time in an area where Lyme disease is common, if they spend time outdoors where they could get bitten by an infected tick, and if they have symptoms characteristic of Lyme disease.

## **Treatment of Lyme disease**

- Comprehensive evidence-based guidance for the prevention, diagnosis, and treatment of Lyme disease
- Antibiotic treatment duration of 10 days 4 weeks, depending on clinical manifestation
- Recommend against additional antibiotic therapy for patients with prolonged symptoms following treatment







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## **Navigating referrals**

- Can be helpful to consult specialists to answer specific questions or for help managing specific symptoms
- Ensure follow-up plan in place and coordination with primary care provider to avoid contributing to medical wandering
- AMA toolkit includes example referral letter

### **Prolonged symptoms – Clinical considerations**

- Patients are ill, some quite disabled
- Effective treatment remains elusive; studies have shown that prolonged courses of antibiotics do not offer lasting benefit over placebo
- Many patients feel being dismissed by mainstream providers
- Patients may seek out alternate providers who sometimes recommend unproven and even dangerous treatments
- Misinformation about Lyme disease is common in general public and online spaces which can be confusing for both patients and providers

## **Guiding clinical principles**

- Take time to hear the patient; validate their symptoms and experiences
- Each clinical encounter is an opportunity to educate and learn
- Follow evidence-based guidance for the diagnosis and treatment of Lyme disease
- Consider using resources in the AMA toolkit to improve clinical care of patients with prolonged symptoms and concerns about Lyme disease
- Ensure the patient has follow-up visits scheduled to remain engaged in care

## **Thank You**

For more information, contact CDC 1-800-CDC-INFO (232-4636) TTY: 1-888-232-6348 <u>cdc.gov</u> Follow us on X (Twitter) @CDCgov & @CDCEnvironment

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the U. S. Centers for Disease Control and Prevention.



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#### Joining the Q&A Session

#### Alison Hinckley, PhD

Lead, Epidemiology and Surveillance Team Bacterial Diseases Branch Division of Vector-Borne Diseases Centers for Disease Control and Prevention

 Christina Nelson, MD, MPH, FAAP Medical Officer, Bacterial Diseases Branch Division of Vector-Borne Diseases Centers for Disease Control and Prevention

 Paul Mead, MD, MPH Branch Chief, Bacterial Diseases Branch Division of Vector-Borne Diseases Centers for Disease Control and Prevention

### **To Ask a Question**

- Using the Zoom Webinar System
  - Click on the "Q&A" button
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- If you are a patient, please refer your question to your healthcare provider.
- If you are a member of the media, please direct your questions to CDC Media Relations at 404-639-3286 or email <u>media@cdc.gov</u>.

#### TRAIN

- January 1, 2024: Move from Training and Continuing Education Online (TCEO) to CDC TRAIN (<u>https://www.train.org/cdctrain</u>).
- Existing Activities: Continue to use TCEO for existing activities that have CE set to expire in 2024, since these courses will not move to CDC TRAIN. You may also use TCEO for existing activities with CE set to expire in 2025, before the courses transition to CDC TRAIN sometime next year. If you begin one of these courses in TCEO, we will let you know when the course will move to CDC TRAIN.
- Transcripts & Certificates: You can access and download CE transcripts and certificates in TCEO through the end of 2025.
- Instructions will be available on both platforms and a learner support team will be available to answer questions.

#### **Continuing Education**

- All continuing education for COCA Calls is issued online through CDC TRAIN at CDC TRAIN (<u>https://www.train.org/cdctrain</u>).
- Those who participate in today's COCA Call and wish to receive continuing education please complete the online evaluation by October 21, 2024, with the course code WC4520R-091924. The registration code is COCA091924.
- Those who will participate in the on-demand activity and wish to receive continuing education should complete the online evaluation between
   October 22, 2024, and October 22, 2026, and use course code WD4520R-091924. The registration code is COCA091924.

#### Today's COCA Call will be Available to View On-Demand

- When: A few hours after the live call ends\*
- What: Video recording
- Where: On the COCA Call webpage
  - <u>https://emergency.cdc.gov/coca/calls/2024/callinfo\_091924.asp</u>

\*A transcript and closed-captioned video will be available about one week after the live session.

### **Upcoming COCA Calls & Additional Resources**

- Continue to visit <u>https://emergency.cdc.gov/coca/</u> to get more details about upcoming COCA Calls.
- Subscribe to receive notifications about upcoming COCA calls and other COCA products and services at <u>emergency.cdc.gov/coca/subscribe.asp</u>.

#### Thank you for joining us today!



#### http://emergency.cdc.gov/coca

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