# Lyme Disease Surveillance in North Carolina 2008-2014

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### Lyme Disease Surveillance in North Carolina 2008-2014

- Wake AHEC requires all speakers to disclose any relevant financial conflicts of interest.
- Carl Williams and Megan Sanza have no relevant financial conflicts of interest to disclose.

### Objectives

- 1. Review Lyme disease (LD) basics (brief)
- 2. Present surveillance findings, 2008-2014
- 3. Look at data completeness, accuracy, and reporting processes
- 4. Suggestions for improving Lyme Disease reporting

#### Overview

- Tick-borne illness caused by Borrelia burgdorferi
- Symptoms may vary significantly
- Early manifestation 3-30 days following tick bite
  - o Fatigue, chills, fever, HA, muscle and joint aches
  - o Erythema migrans (EM) rash
- Dissemination/late manifestation if not treated early
  - o May affect heart, joints, nervous system
- Cases caught early enough can be treated successfully with antibiotics; however 10-20% of patients experience symptoms that persist after antibiotics (PTLDS)

## Post-treatment Lyme Disease Syndrome (PTLDS)

- In 10-20% of treated patients, symptoms can linger months to years after treatment with antibiotics
- Symptoms may include muscle and joint pains, cognitive difficulties, sleep disturbances or fatigue
- The cause for these symptoms is <u>unknown</u>
- Some evidence to suggest caused by autoimmune response (infection cleared, but person's immune system still responding)
- Studies show continuing antibiotic therapy is not helpful

#### LD Case Definition

- For most N.C. counties, case definition is met by having both clinical and lab requirements met.
- N.C. counties designated as <u>endemic</u> no longer need lab requirements met if EM rash is present (Haywood, Wilkes, Guilford, Alleghany, Wake)
- Physician diagnosis of disease is acceptable if clinical criteria is not met (will still need lab criteria met).

If you feel you need assistance understanding LD case investigation, surveillance requirements or laboratory testing please contact Jodi Reber at (919) 715-5416.

### Lyme Disease in North Carolina

2013 Incidence Rate per 100,000 = 0.4 (CDC)

- Fairly low incidence, but significant public interest
- Treatment for each case is not always timely

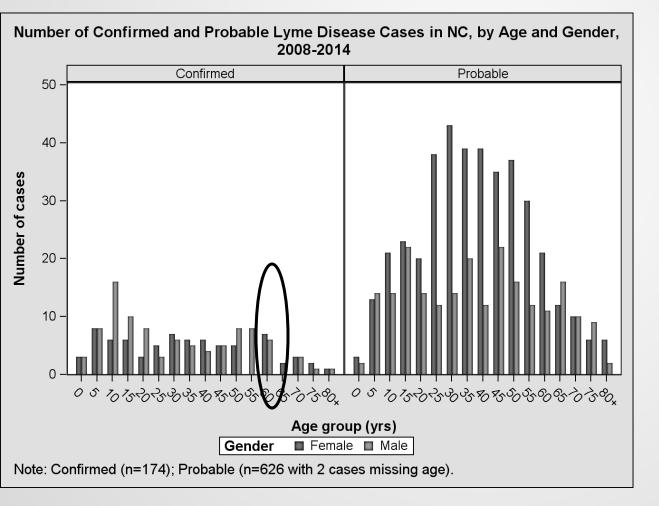
	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Pennsylvania	32.1	34.6	26.1	32.1	30.7	39.3	26	37.2	32.5	39
Maryland	16	22.1	22.2	45.8	31	25.7	20.1	16.1	18.9	13.5
Virginia	2.9	3.6	4.7	12.4	11.4	8.9	11.4	9.3	9.8	11.2
West Virginia	2.1	3.4	1.5	4.6	6.6	7.9	6.9	5.8	4.4	6.3
Georgia	0.1	0.1	0.1	0.1	0.4	0.4	0.1	0.3	0.3	0.1
South Carolina	0.5	0.4	0.5	0.7	0.3	0.5	0.4	0.5	0.7	0.7
<b>North Carolina</b>	1.4	0.6	0.4	0.6	0.2	0.2	0.2	0.2	0.3	0.4
Tennessee	0.3	0.1	0.2	0.5	0.1	0.2	0.1	0.1	0	0.2
U.S. Incidence	6.7	7.9	8.2	9.1	9.4	9.8	7.3	7.8	7	8.6

#### Surveillance Data Notes

- Very broad range of clinical manifestations
  - Large investigation effort with low yield of reporting (for 2014, 866 cases investigated in NC EDSS with only 172 reported ....20%)
  - EM rash indicative of early disease
  - EM observed by HCP is most reliable indicator of true Lyme disease
- Source of illness identification dates vary
  - Symptom onset, laboratory testing, date of diagnosis by HCP, date of report to public health
- Data presented for confirmed and probable cases where applicable, but only confirmed presumed to have true disease

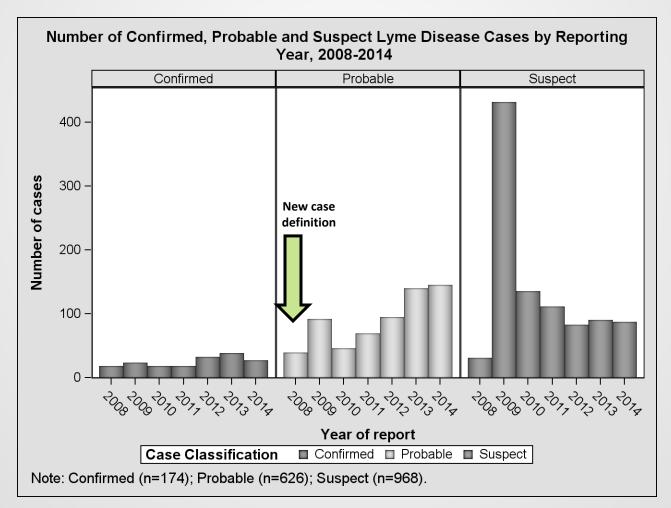
### Cases by Age and Gender

- Boys 10-14 years have the most cases reported in North Carolina
- This is similar to CDC's 2013 national findings of boys 5-9 years
- Probable cases most common among females, but more age variation



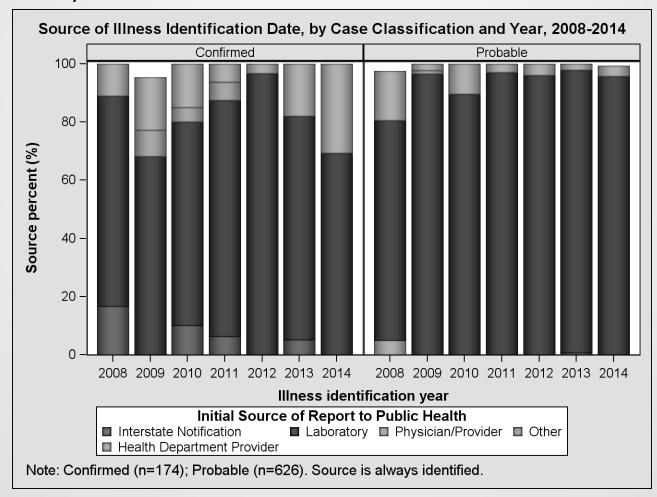
### Case Reporting Since 2008

- Probable case definition first introduced in 2008
- After 2009, fewer cases classified as Suspect



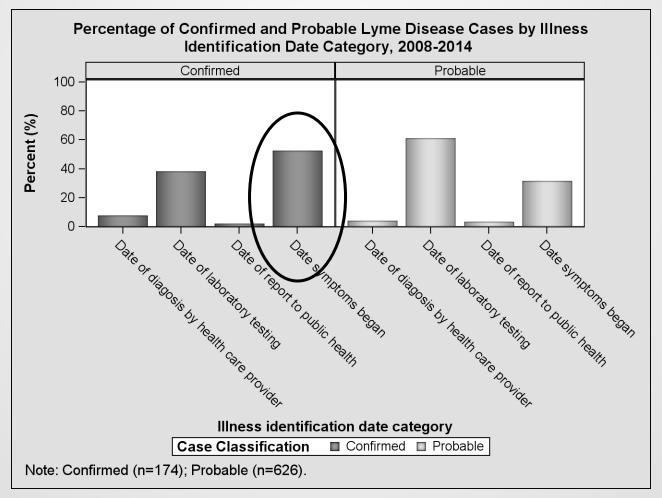
### Source of Initial Report to Public Health

- Lyme disease identified through a variety of sources in North Carolina
- ELR feeds are by far the most common source limited case information



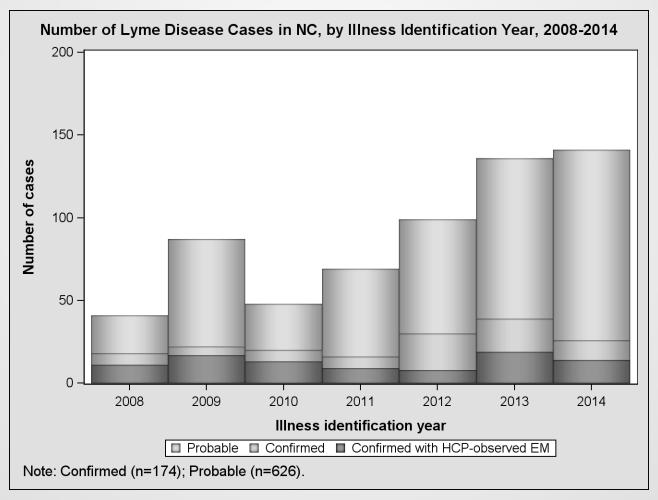
# Cases by Illness Identification Date Category

 Confirmed cases have a larger proportion symptom onset illness ID dates; more complete information



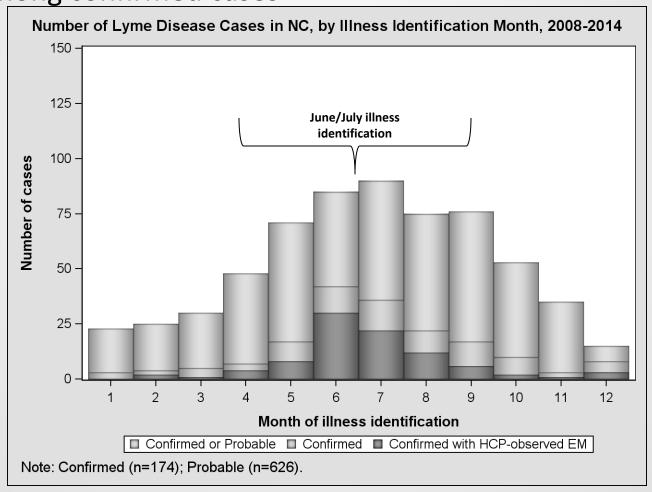
#### Cases Reported by Year

- Steady increase among probable cases since 2008
- Confirmed case numbers fairly consistent 2008-2014, with slight increases over the last 3 years



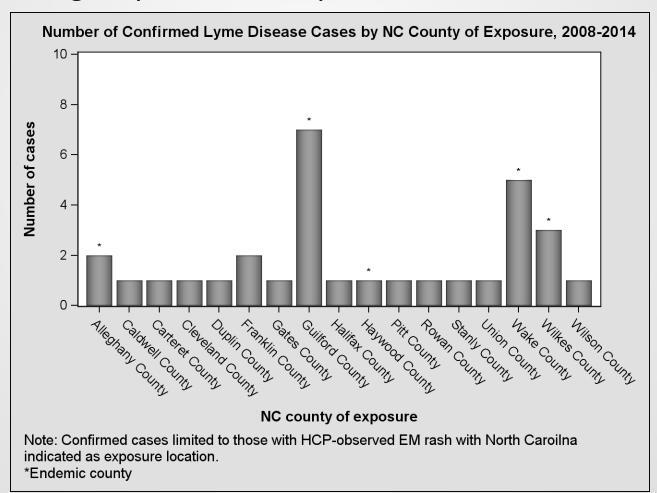
#### Cases Reported by Month

- Most cases reported during summer months, May-September
- Clear seasonality similar to national data, more notable among confirmed cases



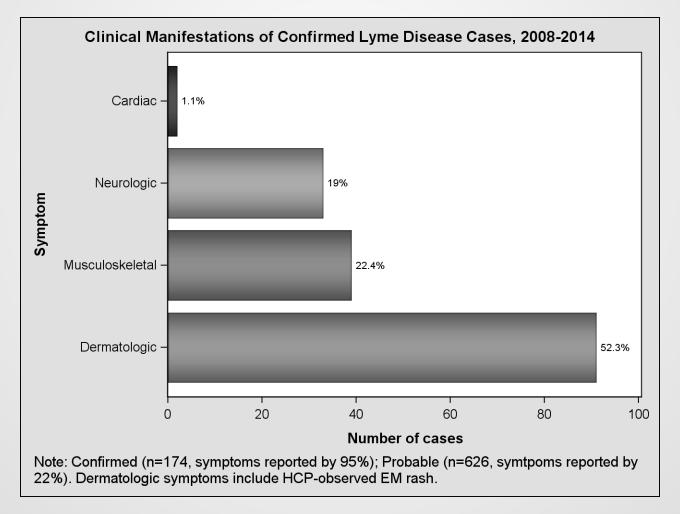
### Cases by County

- Endemic county = 2 or more confirmed cases with no known travel during 32 days prior to onset
- 5 counties: Alleghany, Guilford, Haywood, Wake, Wilkes



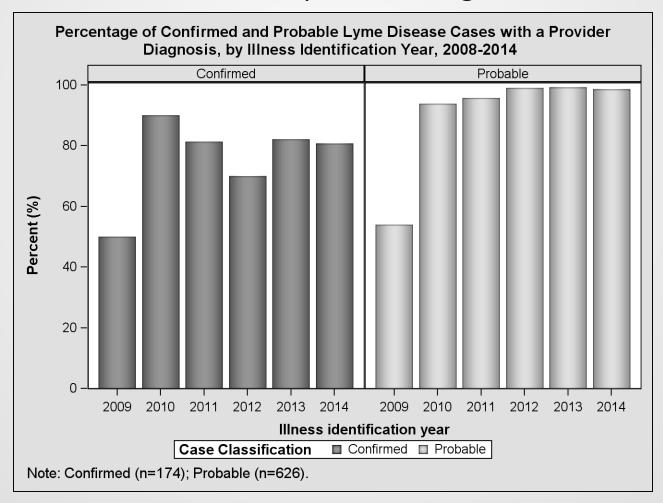
#### Reported Symptoms

- EM rash most common, followed by musculoskeletal
- Consistent with national CDC findings through 2013



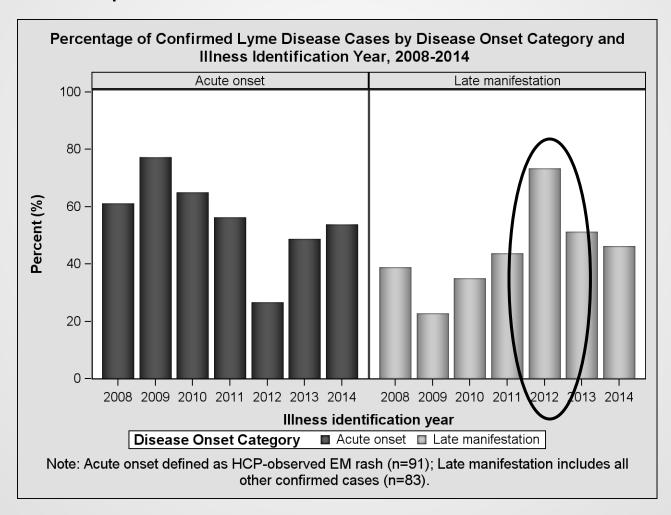
#### Cases by Provider Diagnosis

- Probable case definition added in 2008, requires provider diagnosis (100% of cases beginning in 2012)
- 80% of confirmed cases have a provider diagnosis



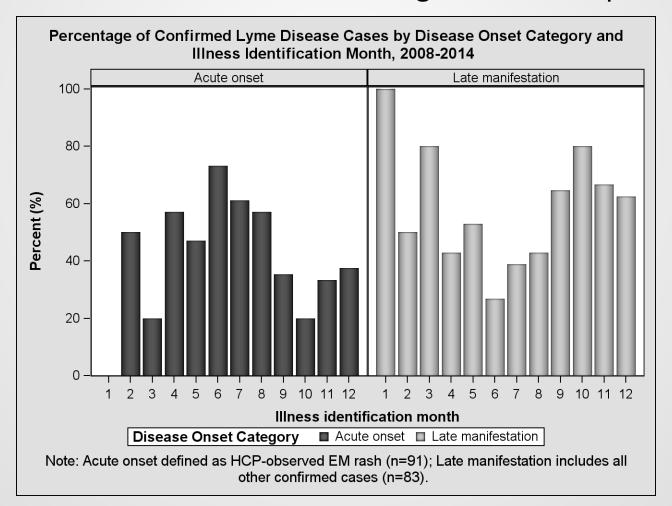
#### Cases by Onset and Year

- Most cases are acute onset cases; more apparent 2008-2011
- 2012 is an exception with almost 80% of late manifestations



#### Cases by Onset and Month

- Seasonality is somewhat apparent when looking at cases by onset category; acute increases during summer months
- All Jan cases are late manifestation along with most Sep-Dec



# Data Reporting and Data Quality

- Most cases are initially reported through ELR feeds; patient information often sparse
- Provider communication is encouraged but always fruitful;
   patient interviews for LD are less common than other diseases
- Use 2008-2014 data to look more closely at data flow and entry for LD events in NC EDSS
- Analyze missing key fields and variation in how data have been entered
- Underlying goal to improve efficiency of data entry and completeness and quality of data

# Data Completeness: Demographics

- Confirmed case data more complete than probable, as might be expected
- Race is most common missing demographic

	Number Missing (%) - PROBABLE	Number Missing (%) - CONFIRMED
AGE	2 (12)	0
GENDER	1 (2)	1 (.5)
RACE	19 (3)	2 (1)

### Why Cases Were Tested for Lyme Disease

Reason Selected for Testing	Number Tested (%)
No reason selected	30 (17%)
Symptomatic of disease	128 (74%)
Symptomatic of disease; Tick bite without symptoms of disease	9 (5%)
Tick bite without symptoms of disease	19 (3)
Other*	8 (5%)

<sup>\*</sup>Of these 8, 5 had notes that indicated LD symptoms were present.

### Improvements to Data Collection

- Source of illness Identification date:
  - o Best is illness onset date; if unknown, use lab testing date
  - Avoid using Date of Report to Public Heath
- Is patient symptomatic for disease?
  - o If Lyme disease testing is for a general screen then the answer is no.
- EM rash must have a size to count and be diagnosed by the physician.
  - o EM rash must be greater than 5cm
- Illness greater than 30 days should have a positive IgG Western Blot lab...or it may not be counted.
- Must answer the "Did Patient Survive" question in clinical package.

### Improvement to Data Collection

- If a non-endemic county has a new case of locally acquired LD (EM rash + Labs), DPH would like to confirm labs by having IgG Western Blot run if not already done.
- Free laboratory testing can be performed at CDC for these cases.
  - Locality can perform testing and send to CDC via NC SLPH. (Locality must decide if they will perform venipuncture at no charge)
  - o Results can take some time and are only used for surveillance purposes
  - o A negative result will not change case classification from original lab results

### Physician and Public Outreach

 DPH provides a yearly memos to provider to discuss LD and the other tick and mosquito illness present in N.C. Please distribute these to the providers in your community. These memos are available on our websites at:

<a href="http://epi.publichealth.nc.gov/cd/arbo/providers.html">http://epi.publichealth.nc.gov/cd/arbo/providers.html</a> and <a href="http://epi.publichealth.nc.gov/cd/ticks/lhds.html">http://epi.publichealth.nc.gov/cd/ticks/lhds.html</a>

- DPH has tickborne booklets available for provider use
- Tickborne posters are also available that should be widely utilized in physicians offices, parks, outdoor trails, etc.

(Please see Jodi at the handouts booth)

#### Summary

- Surveillance numbers appropriately reflect revised case definition after 2008
- Confirmed cases static since 2008
- Late manifestation diagnoses have increased since 2008; highest in 2012
- North Carolina case distribution mimics expected seasonality of LD
- Similar demographic and symptom distribution 2008-2014 to national findings 2001-2010
- Challenges with regard to diagnosis and exposure information

#### Resources

- NC EDSS
- http://www.cdc.gov/lyme/index.html
- http://epi.publichealth.nc.gov/cd/ticks/lhds.html