

# CDC PUBLIC HEALTH GRAND ROUNDS

## Surveillance for Emerging Threats to Pregnant Women and Infants: Data for Action



Accessible version: <https://www.youtube.com/watch?v=0LsGory9nPk>

**September 18, 2018**



**U.S. Department of  
Health and Human Services**  
Centers for Disease  
Control and Prevention

# Mind the Gap: Missed Opportunities to Prevent Congenital Syphilis



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U.S. Public Health Service

*Epidemiologist, Division of STD Prevention*

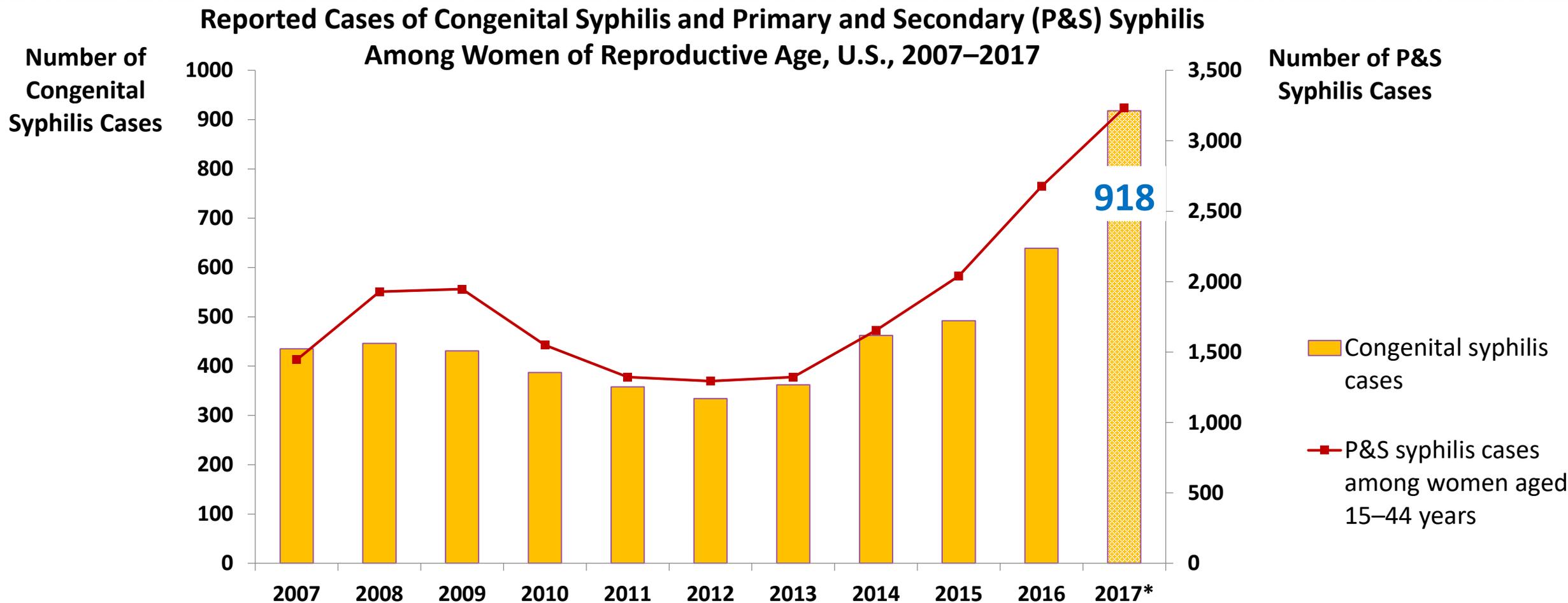
National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention

Centers for Disease Control and Prevention



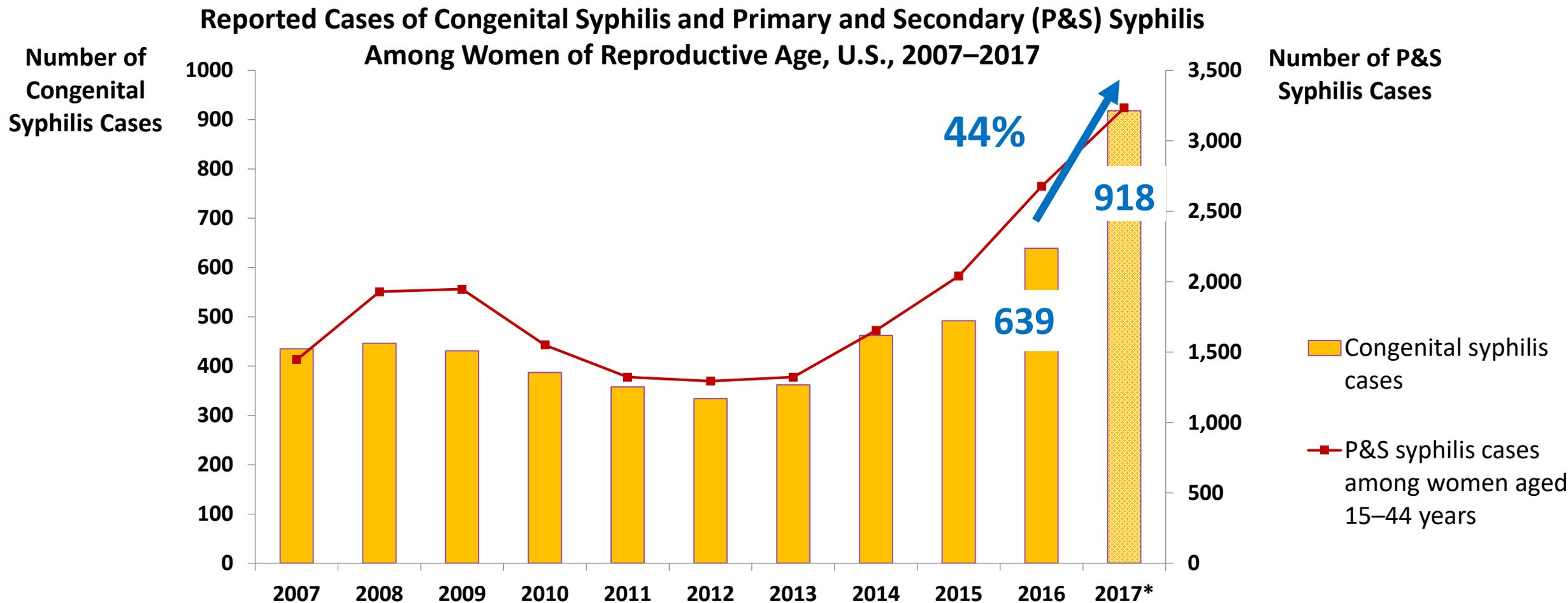
U.S. Department of  
Health and Human Services  
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# Congenital Syphilis Cases Are Increasing, as are Primary and Secondary Syphilis Cases Among Women



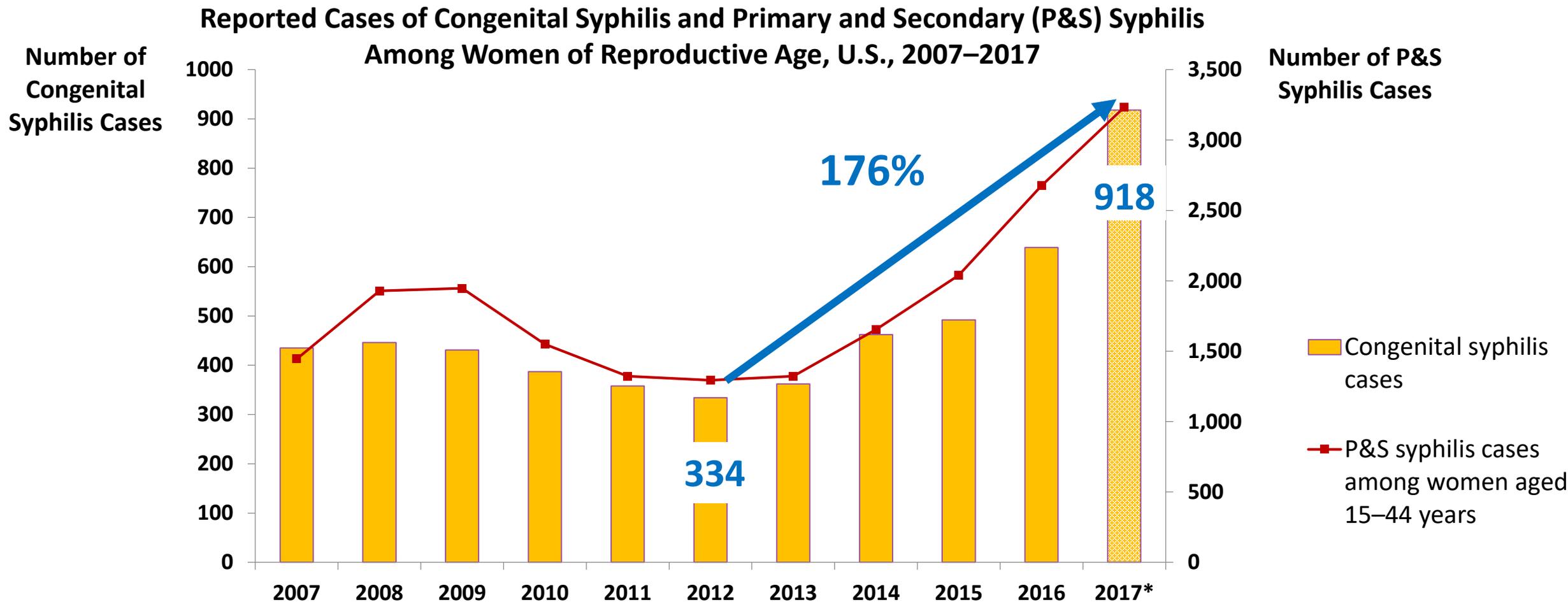
\*2017 national case report data are preliminary as of June 30, 2018

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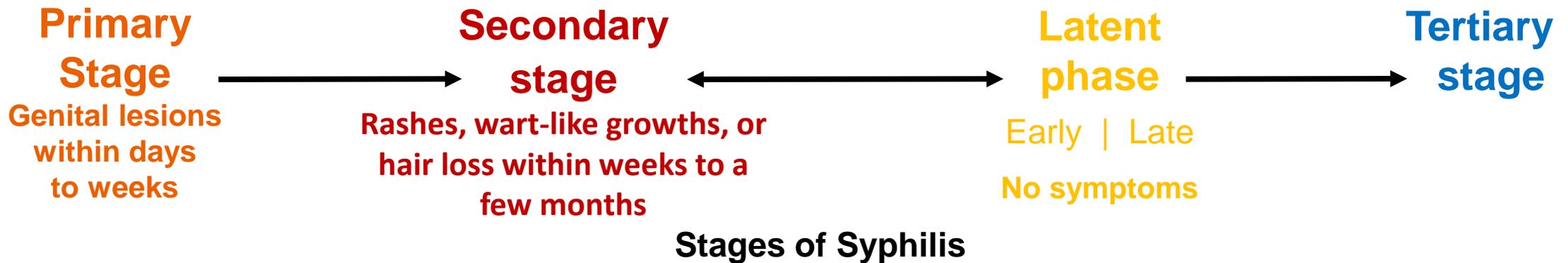
# Congenital Syphilis Cases Are Increasing, as are Primary and Secondary Syphilis Cases Among Women



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# Syphilis Is a Complicated Bacterial Infection

- Syphilis is caused by the bacteria *Treponema pallidum*
- Signs and symptoms of early syphilis can be difficult to detect
- Untreated syphilis then enters a latent phase with no symptoms
- Diagnosis is made by medical history, clinical exam, and two blood tests



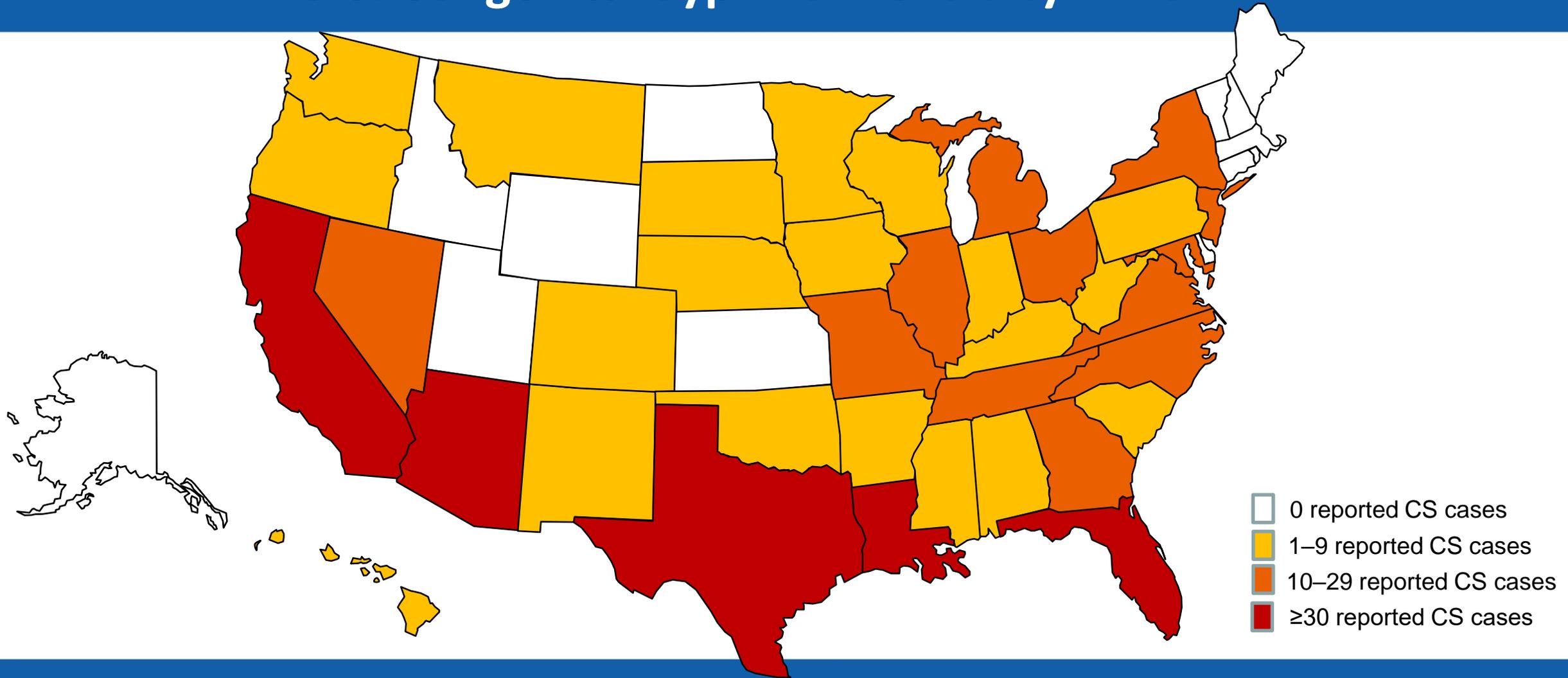
# Syphilis Can Be Transmitted *in utero* If Left Untreated

- **Infected woman can transmit syphilis to the fetus during pregnancy**
  - At any stage of syphilis and any trimester of pregnancy
- **Congenital infection can result in:**
  - Stillbirth and early infant death
  - Infant disorders such as neurologic impairment and bone deformities
- **Adequately treating syphilis during pregnancy can prevent congenital syphilis**



**Newborn with congenital syphilis rash and enlarged liver and spleen (marked in black ink)**

# 5 States Make Up 70% of the U.S. Congenital Syphilis Morbidity in 2017



\*National CS case report data, preliminary as of June 30, 2018; all states reporting

# Prenatal Syphilis Screening Is the Cornerstone of Congenital Syphilis Prevention

- Syphilis is curable using injectable, long-acting penicillin
- Timely detection and treatment are essential for preventing congenital syphilis and its complications
- CDC recommends:

Screening *all* pregnant women for syphilis  
at the first prenatal visit

*AND*

additional screening early in 3<sup>rd</sup> trimester (≈28 weeks)  
if high risk for syphilis or living in an area of high morbidity



# Understanding Risk Factors May Guide Interventions

- **Risk factors for syphilis among women include:**
  - Multiple sex partners
  - History of incarceration
  - Substance use disorders
  - History of exchanging sex for drugs/money/housing
  - Having a sex partner with multiple sex partners or a history of incarceration
- **Among pregnant women with syphilis, late or no prenatal care is significantly associated with delivering an infant with congenital syphilis**

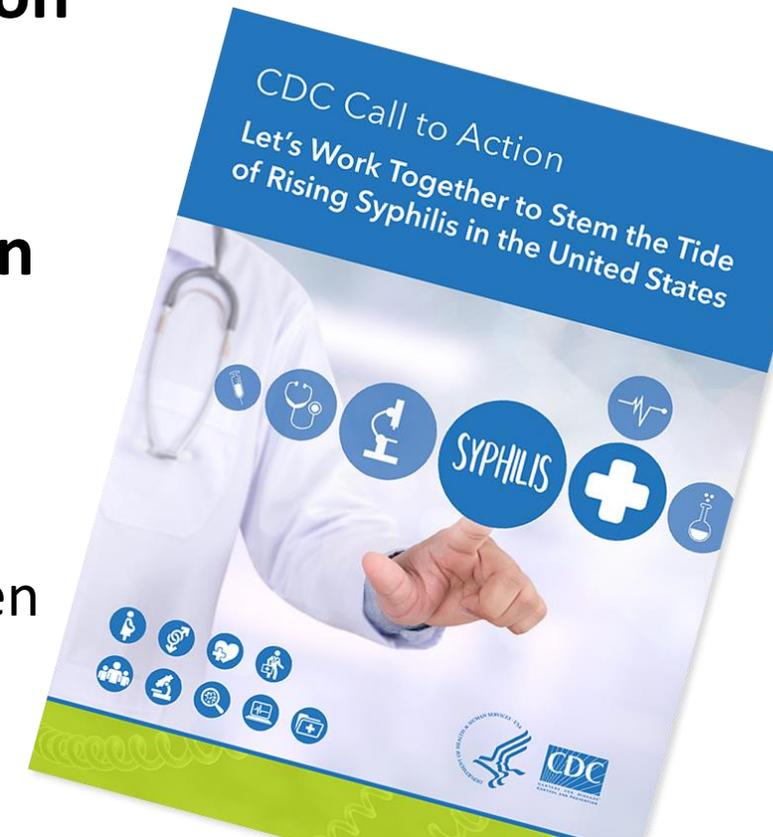
# Four Key Opportunities To Prevent Congenital Syphilis (CS)

<b>Missed Opportunities to Prevent Congenital Syphilis</b>		<b>N</b>	<b>%</b>
Mothers of Reported Congenital Syphilis Cases (n=628), U.S., 2016			
<b>1. Prenatal Care:</b>	Received late or no prenatal care and not screened in time	215	34%
<b>2. Screening:</b>	Received prenatal care, but not screened in time to treat adequately for CS	51	8%
<b>3. Treatment:</b>	Positive initial screening test, but inadequately treated for CS	111	18%
<b>4. Re-screening:</b>	Negative initial screening test, but later infected and detected at delivery	101	16%
<b>Other</b>		48	8%
<b>Missing Data:</b>	Unknown/inadequate testing or treatment data	102	16%
<b>Total</b>		628	100%

Late prenatal care is < 30 days prior to delivery; timely screening is ≥ 30 days prior to delivery

# A National “Call to Action” for Syphilis

- **In April 2017, CDC published a “Syphilis Call to Action”**
  - Outlines activities to control adult syphilis and prevent congenital syphilis
- **Preventing congenital syphilis requires coordination among healthcare providers, public health departments, and pregnant women**
  - Improve pregnancy status verification among women with syphilis and prospective data collection for pregnant women
  - Identify key surveillance gaps and opportunities for collaboration



# CDC Pilots Ways to Improve Case Ascertainment and Collection of Risk Factors

- In October 2017, CDC awarded \$4 million to nine high-morbidity project areas to address congenital syphilis
- The goals of the supplemental funding include
  - Sustainable improvements to congenital syphilis-related activities
  - Strengthened congenital syphilis prevention through *prospective* information-gathering and interventions
  - Strengthened congenital syphilis prevention through *retrospective* activities to identify opportunities for change



# Gaps in Current Surveillance System Limit Interpretation and Action

## Current methods of surveillance:

- Lack **timely ascertainment of pregnancy status** for women with syphilis
- Lack **negative syphilis test results** that may allow health departments to monitor rates of screening and re-screening within prenatal care
- Lack **linkage between female and congenital syphilis case reports** that may allow an understanding of maternal risk factors
- Lack **information about syphilis-exposed infants** who fail to meet the congenital syphilis case classification, meaning cases cannot be compared to non-cases
- Lack significant **detail on fetal syphilis or long-term outcomes** for syphilis-exposed infants

# Longitudinal Surveillance May Present Opportunities, Including Collaboration with Other Pregnancy-related Conditions

- **Longitudinal surveillance centered around pregnant women with syphilis may be helpful**
  - May ensure more complete congenital syphilis case ascertainment
  - May allow us to examine additional maternal and fetal factors during pregnancy
  - May allow us to follow infants post-partum and document outcomes
- **Timely entry of pregnant women into longitudinal surveillance may also allow for more real-time health department intervention**
- **Longitudinal surveillance systems may be integrated across diseases**

# Using Birth Defect Surveillance to Monitor Zika During Pregnancy

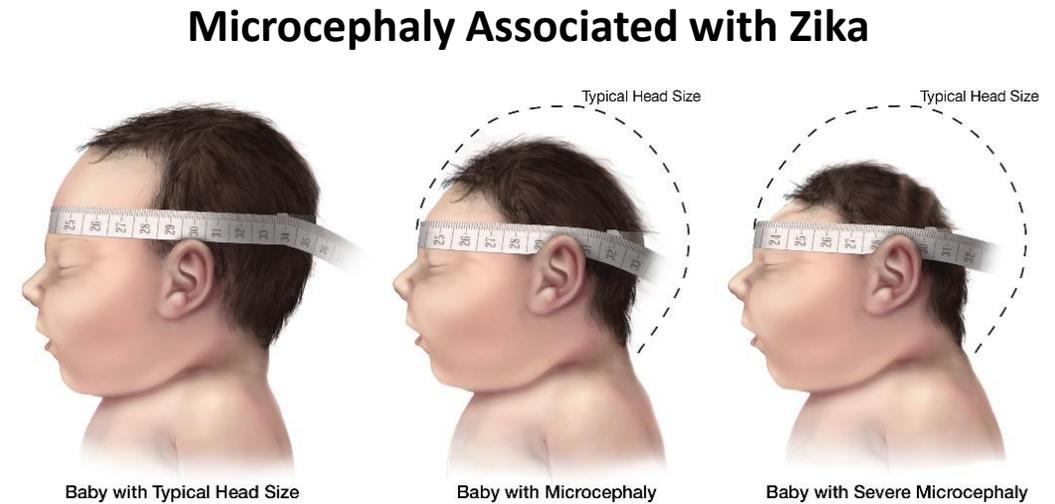


**Mahsa Yazdy, PhD, MPH**

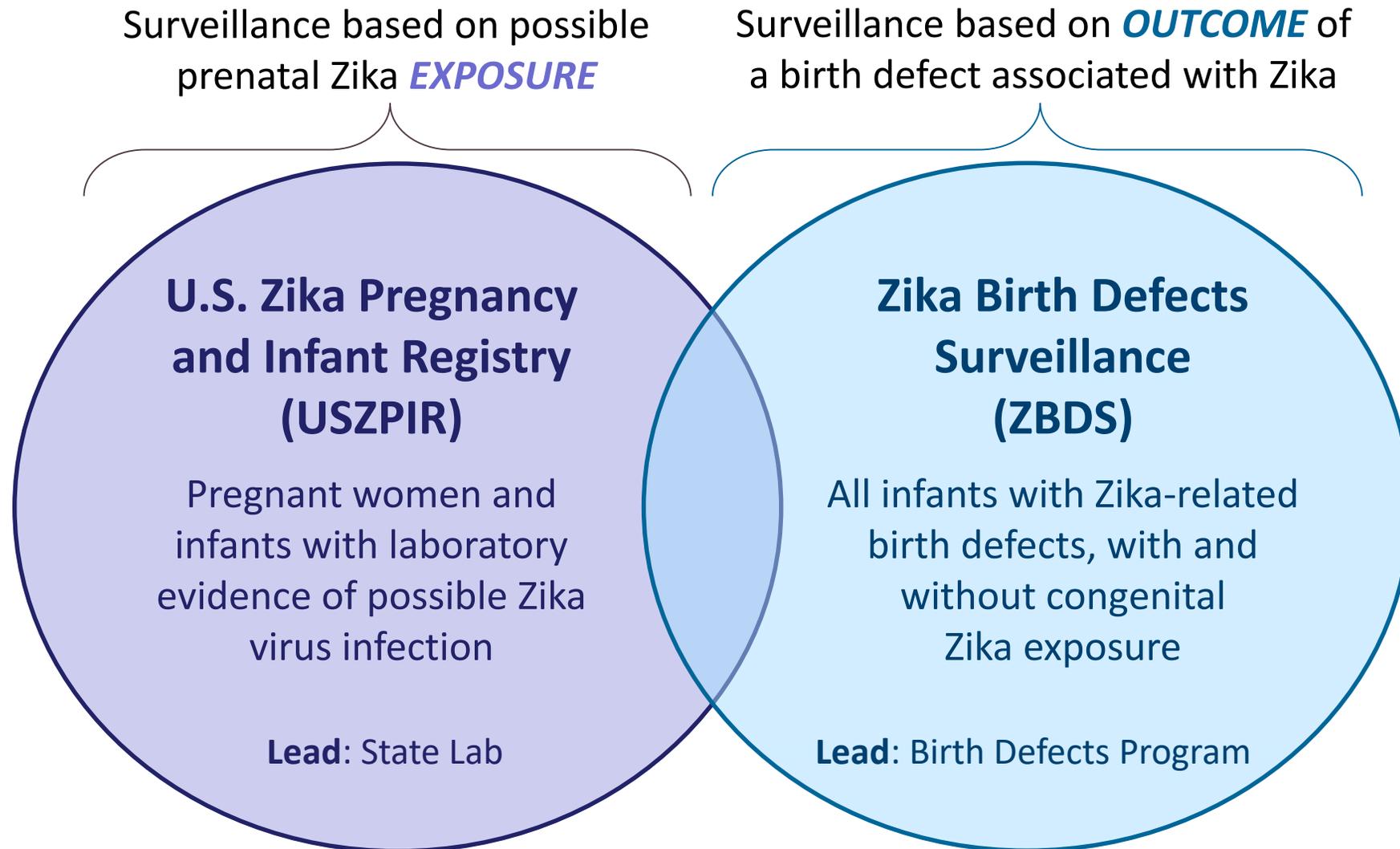
*Director, Massachusetts Center for Birth  
Defects Research and Prevention  
Massachusetts Department of Public Health*

# Zika Virus Infection during Pregnancy

- **Mosquito-borne flavivirus**
  - Related to dengue, yellow fever, and West Nile
- **80% asymptomatic, and infection induces lifelong immunity**
- **In 2014–2015, spread to the Americas and the Caribbean**
  - Largest Zika virus outbreak ever recorded
- **Zika virus infection during pregnancy can cause congenital Zika syndrome**
  - A distinct pattern of birth defects among fetuses and newborns, including microcephaly and other severe brain and birth defects

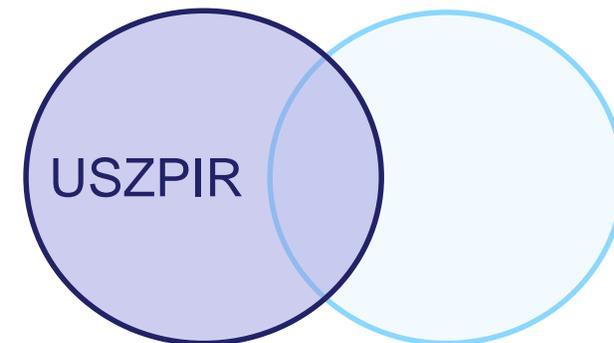


# Two-Pronged Surveillance Captures Impact of Zika



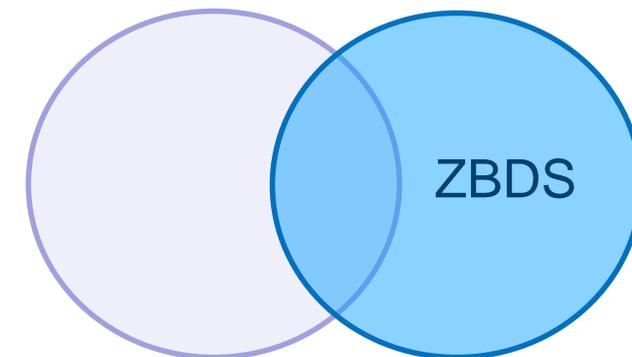
# U.S. Zika Pregnancy and Infant Registry (USZPIR)

- **Lead: Bureau of Infectious Disease and Laboratory Sciences**
- **Priority: Testing pregnant women and providing education**
- **Data collected on maternal health history, pregnancy exposures, neonatal outcomes, and infants followed through age 2**
- **In Massachusetts, all infections travel related**
  - 174 pregnant women reported, 169 infants being followed
- **Collaboration with Birth Defects Monitoring Program**
  - Complete maternal and neonate assessment forms
  - Notify program of pregnant women with positive test
  - Notify program if birth defect identified during follow-up



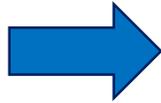
# Zika Birth Defects Surveillance (ZBDS)

- **Lead: Birth Defects Monitoring Program**
- **Priority: Rapid surveillance of infants with Zika associated birth defect, regardless of Zika exposure**
- **Inform affected families of MCH services (e.g., early intervention, WIC)**
- **In Massachusetts**
  - 690 infants and fetus identified (1/1/16–5/31/18)
- **Collaboration with state lab**
  - Notify lab if mention of Zika exposure in medical records
  - Cross-check with lab to see if cases are in USZPIR, or if cases had negative Zika tests

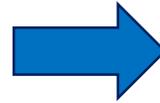


# Massachusetts Birth Defects Monitoring Program is an Active, Population-based Birth Defects Surveillance

Receive reports of cases



Abstractors review hospital records



Abstract info on cases



Clinical review and classification of cases



## Data sources

Birthing and non-birthing hospitals

Prenatal reporters

Commercial laboratories

Selected outpatient records

Emergency departments

Pathology departments

Vital records

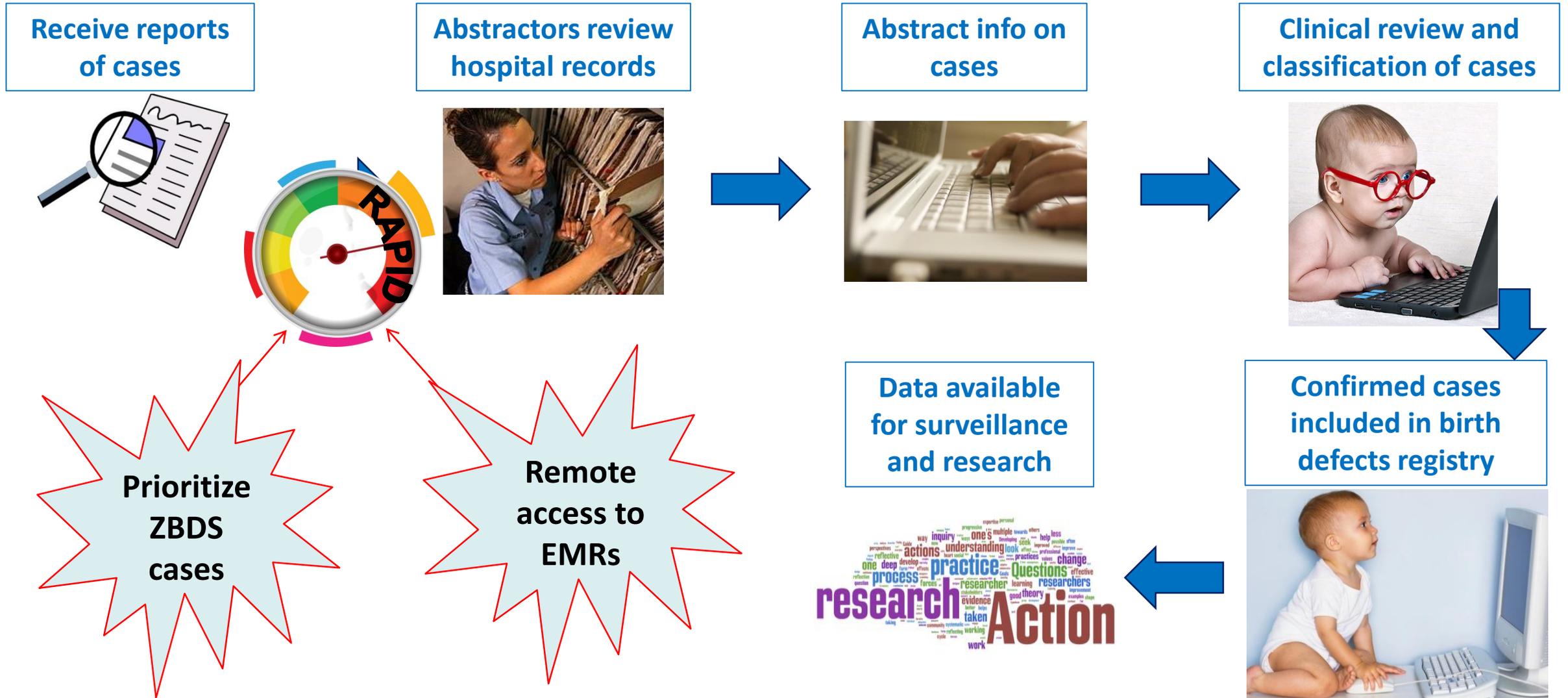
(i.e., birth, death, and fetal death certificates)

Data available for surveillance and research

Confirmed cases included in birth defects registry



# Massachusetts Birth Defects Monitoring Program is an Active, Population-based Birth Defects Surveillance



# Increased Timeliness of Zika Birth Defects Surveillance (ZBDS)

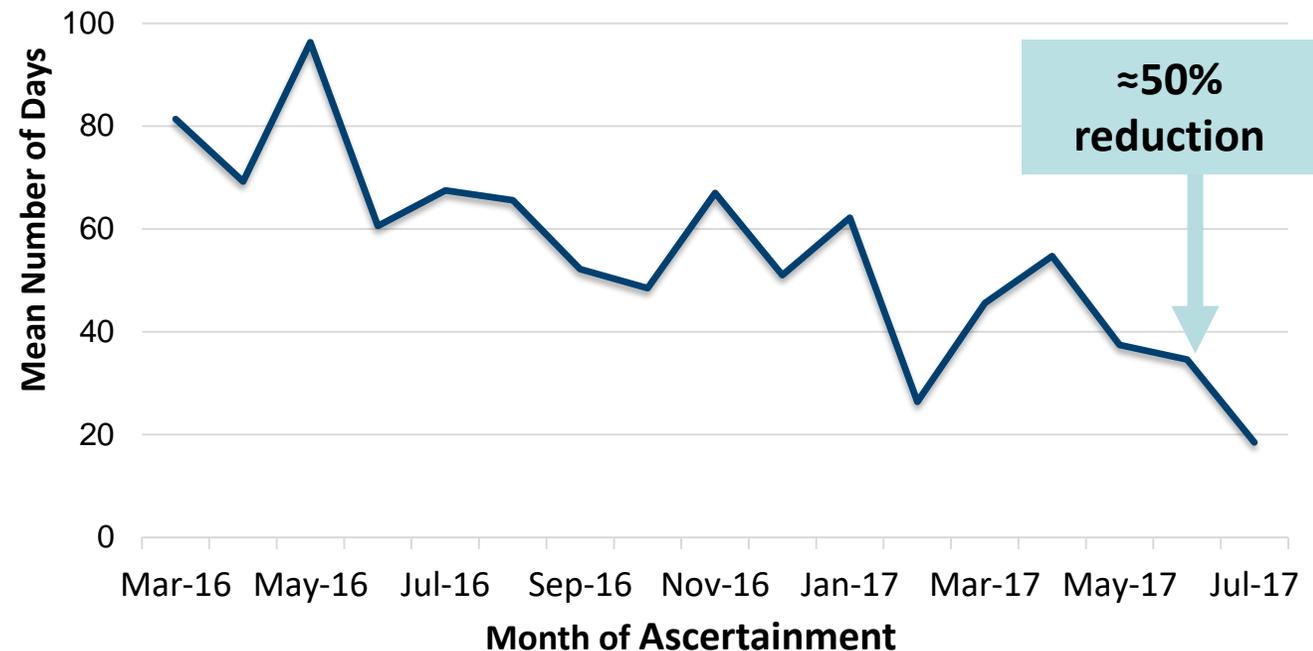
## ➤ Prioritize abstraction of ZBDS cases

- Push Zika related birth defects cases to the top of abstraction list

## ➤ Remote access to EMR

- 18 hospitals with remote access
  - 6 hospitals pending
- Access at 4 tertiary hospitals accounted for 35% of abstractions

Mean Days Between Ascertainment & Abstraction, Massachusetts ZBDS



# Data Uses: Establishing the Baseline Prevalence of Birth Defects

## ➤ From USZPIR

**Among completed pregnancies in the U.S. with lab evidence of possible Zika infection**

- 6% fetuses or infants had Zika-associated birth defects
- In symptomatic and asymptomatic women, similar proportion with birth defects (**≈6%**)
- Among women with infection in the 1st trimester, Zika-associated birth defects reported in **11%**

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## ➤ From Established Birth Defects Surveillance Systems

- Baseline prevalence pre-Zika:  
≈3 per 1000 live births
- Prevalence for pregnancies with Zika exposure: ≈60 per 1000 live births
  - ▣ **20-fold increase in Zika-related birth defects**
  - ▣ **33-fold increase for brain abnormalities or microcephaly**
- Demonstrate the importance of birth defects surveillance

# Update on Zika Surveillance in Massachusetts

- **MA fifth largest Puerto Rican population in U.S.**
  - Families relocating from hurricane-impacted areas
- **Currently assessing needs and gaps**
- **Ongoing goal**
  - Connect families to available maternal child health services
  - Identify families with an infant affected by Zika
  - Notify state lab of potential USZPIR-eligible infant



# Challenges

## ➤ **Establishing standard case definition**

- Review cases to understand common possible phenotypes
- In Massachusetts
  - ❑ Some Zika-associated conditions not previously in surveillance (e.g., intracranial calcifications)
  - ❑ Work with newborn hearing screening to identify infants with congenital deafness

## ➤ **Communication between healthcare providers**

## ➤ **Infants in USZPIR lost to follow-up**

- ❑ 34% lost within first year of life

## ➤ **Long-term outcomes not well understood**



# Successes

- **Early collaboration resulted in a more robust response to Zika**
- **Massachusetts was the first state to send Pregnancy Registry data and among the first group to send Birth Defects Surveillance data to CDC**
- **Improved data quality**
  - e.g., Birth Defects Program abstraction helps link State Lab to pediatricians for later follow-up
- **Jointly organized other activities**
  - e.g., outreach campaign, webinar for providers, and Zika advisory committee
- **Connecting to other programs**
  - e.g., working on linking Pregnancy Registry and Birth Defects Surveillance data to Early Intervention



# A New System for Surveillance and Collaborations Models the Future

- **Provided a model for response to future infectious outbreaks related to birth defects**
- **Facilitated improvements**
  - In our surveillance system
  - In inter-bureau collaboration that will be of use well beyond the Zika epidemic
- **Provided data to evaluate the potential impact of Zika infection during pregnancy**

# Adapting Zika Birth Defects Surveillance to Rapidly Monitor Neonatal Abstinence Syndrome



**Sharon Watkins, PhD**  
*State Epidemiologist and  
Bureau Director*  
Bureau of Epidemiology  
Pennsylvania Department of Health

# Overview

- **How we, as a state with no birth defects surveillance prior to 2016, used Zika Birth Defects Surveillance resources and lessons learned to rapidly respond to an emerging threat—Neonatal Abstinence Syndrome**

**Neonatal Abstinence Syndrome: Newborn withdrawal from prenatal substance exposure**

**Signs and Symptoms of Neonatal Abstinence Syndrome**

**Tremors**

**Irritability**

**Increased muscle tone**

**Poor feeding**

**Seizures**

**High-pitched crying**

**Hyperactive deep tendon reflexes**

**Gastrointestinal tract dysfunction**



# Birth Defects Surveillance Prior to CDC Funding for Zika Birth Defects Surveillance (ZBDS)

- **3,978,497 U.S. live births (2015)**
- **44 states with some type of birth defects surveillance program**
  - 3,712,704 live births covered
- **Six states without a birth defects surveillance program (2015)**
  - Pennsylvania was the largest

States Without Birth Defects Surveillance Program	2015 Live Births
Pennsylvania	141,047
Alabama	59,657
Idaho	22,827
Montana	12,583
South Dakota	12,336
Wyoming	7,765

# Pennsylvania Challenges for Birth Defects Surveillance

- **Legal challenges: No specific legislative authority to make direct requests to hospitals or physicians for cases**
- **Birth certificates: Limited source for birth defects case finding**
- **Hospital discharge data (outsourced): Provides de-identified data**
  - Problematic for following transferred infants
  - No history of state surveillance exists to evaluate validity of coding if case verification is not performed
- **Other sources?**
  - Voluntary reporting
  - Network building

# Zika Birth Defects Surveillance Process

## ➤ Legal authority gained in 2016

- After review, outcomes, such as possible birth defects from a reportable infectious disease, were reportable

## ➤ Surveillance method: Passive + Active

### ● PASSIVE

1. Contact birthing facilities (ICD-10 discharge codes)
2. Process facility-provided case lists to remove non-cases
3. Send final case list for review to facility

### ● ACTIVE

4. Review medical records for case verification and abstraction
5. Record data in REDCap Cloud electronic database



# Birth Defects Surveillance—Initial Activities Timeline

Progress after CDC Zika Birth Defect Surveillance funding began August 2016:



# Neonatal Abstinence Syndrome Surveillance Background

GOVERNOR TOM WOLF

ABOUT ACTION PLAN NEWS ADMINISTRATION

Governor Wolf Declares Heroin and Opioid Epidemic a  
Statewide Disaster Emergency

January 10, 2018

**Three months later... January 2018, the governor declared 90-day state of emergency for the opioid epidemic and asks for**

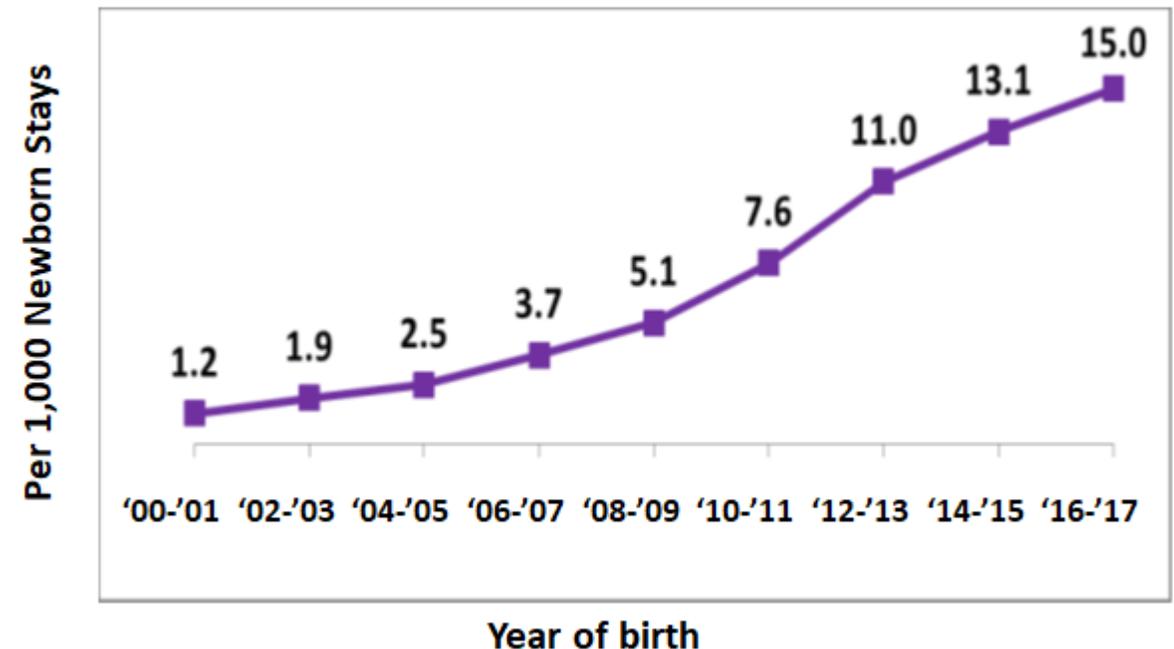
- **Neonatal Abstinence Syndrome: Rapid case ascertainment**



# Neonatal Abstinence Syndrome (NAS) in Pennsylvania

- **Increasing NAS-related hospital stays per 1,000 newborn stays**
- **Hospital inpatient data report from PHCCCC:**
  - Greater than 1,000 percent increase in newborn stays
  - Greater than \$14 million in estimated costs for NAS-related stays in 2017

Rate of Newborn Hospital Stays Related to NAS



2017 estimated costs based on 2013 average Medicaid payments

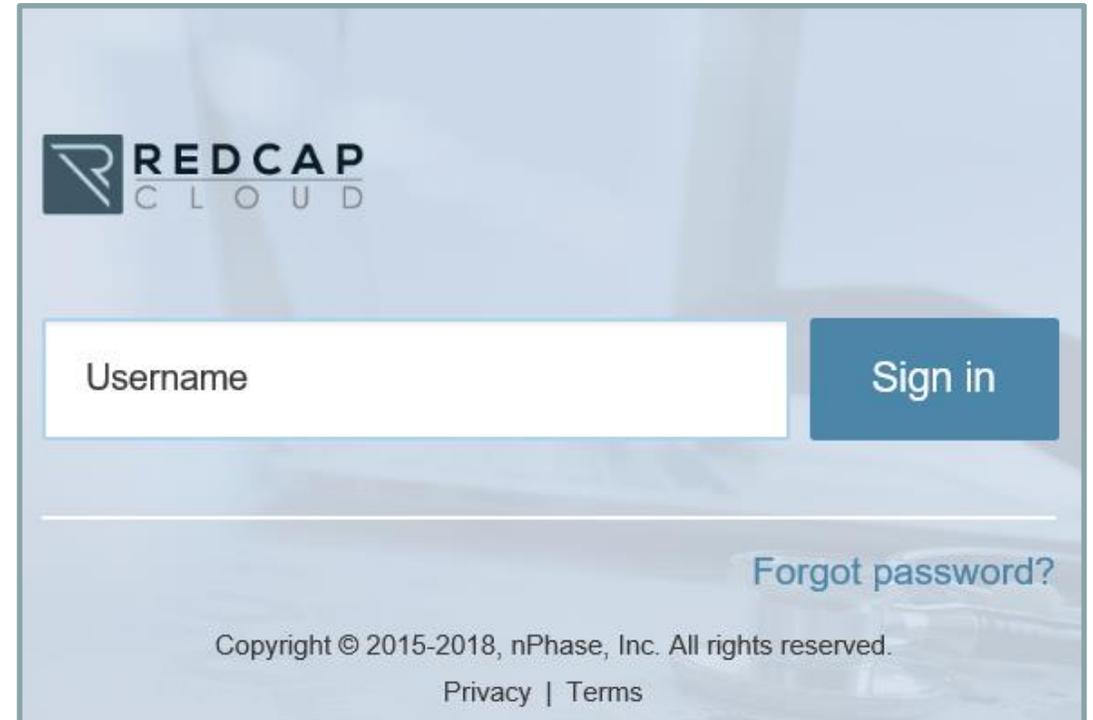
Pennsylvania Health Care Cost Containment Council. (PHCCCC) (2018, March). Hospitalizations for Newborns with Neonatal Abstinence Syndrome.

# Short Term Options

## ➤ Consider options for short/near term data collection:

- PA-NEDSS
- Paper-based report form
- **Web-based system**

## ➤ **X** Web-based for streamlined data collection



The image shows a screenshot of the REDCAP Cloud login interface. At the top left is the REDCAP CLOUD logo. Below it is a white input field labeled 'Username' and a blue 'Sign in' button. To the right of the 'Sign in' button is a link that says 'Forgot password?'. At the bottom of the page, there is a copyright notice: 'Copyright © 2015-2018, nPhase, Inc. All rights reserved.' and two links: 'Privacy | Terms'.

# Leveraging Knowledge Gained from ZBDS

BIRTH DEFECTS SURVEILLANCE		NAS REPORTING
Birth Facilities	→	Birth Facilities
Birth Records Data	→	Birth Records Data
REDCap Cloud Database	→	REDCap Cloud Database

- **Birth Facilities:** Use ZBDS contacts, annual live births data, plus strategy of prioritizing largest birth facilities
- **Birth Records Data:** Apply ZBDS knowledge of data available in infant's medical record
- **REDCap Cloud Database:** Leverage extensive validation performed during ZBDS setup
  - Experience with functional capability
  - Completed user acceptance testing

**DATA PREPAREDNESS**

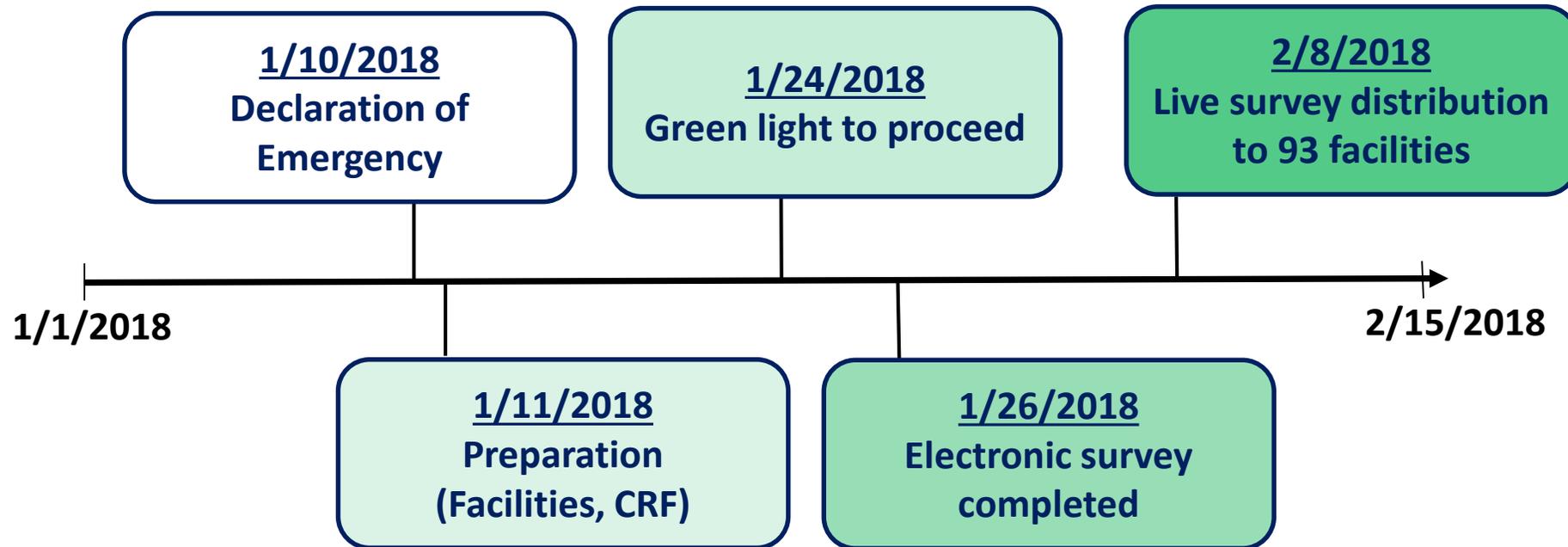
# Creating A Case Report Form

- **Perform literature review**
- **Identify potential users**
- **Consider data available at time of entry**
- **Create defined response sets**
- **Key: Use 'one-page' approach**
  - Visually shortened with skip-patterns and dropdowns
  - Consider variables for collection
  - Balance between:
    1. Robust clinical data
    2. One page template



# Neonatal Abstinence Syndrome (NAS) Data Collection

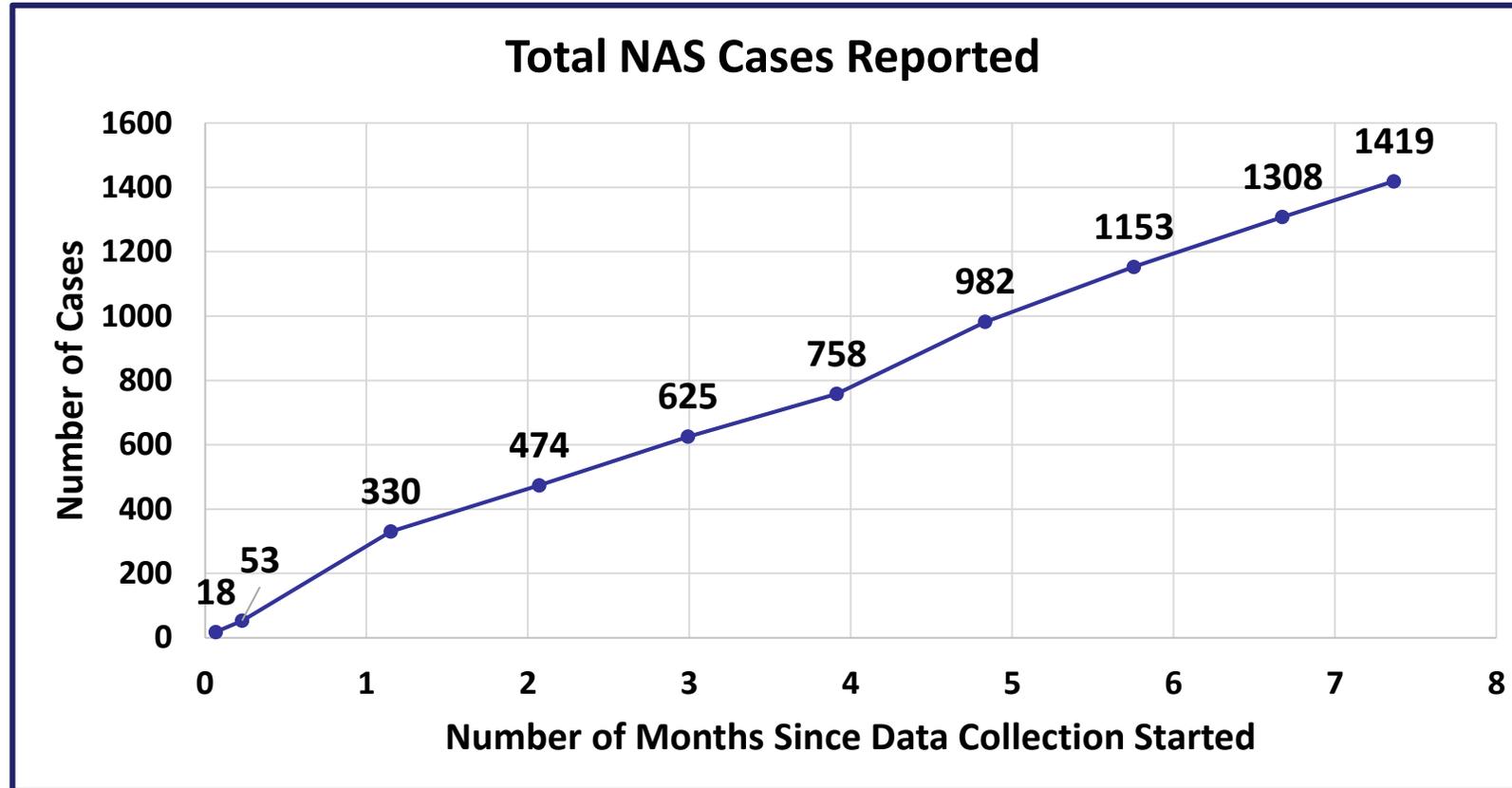
*Rapid case ascertainment began in less than 1 month*



**Case definition:** NAS diagnosed in an infant during the neonatal period (birth to 28 days) who has symptoms of withdrawal from prenatal exposure to opiate drugs either via prescription, medical therapy, or illegal use.

# NAS Data Collection: Number of Cases

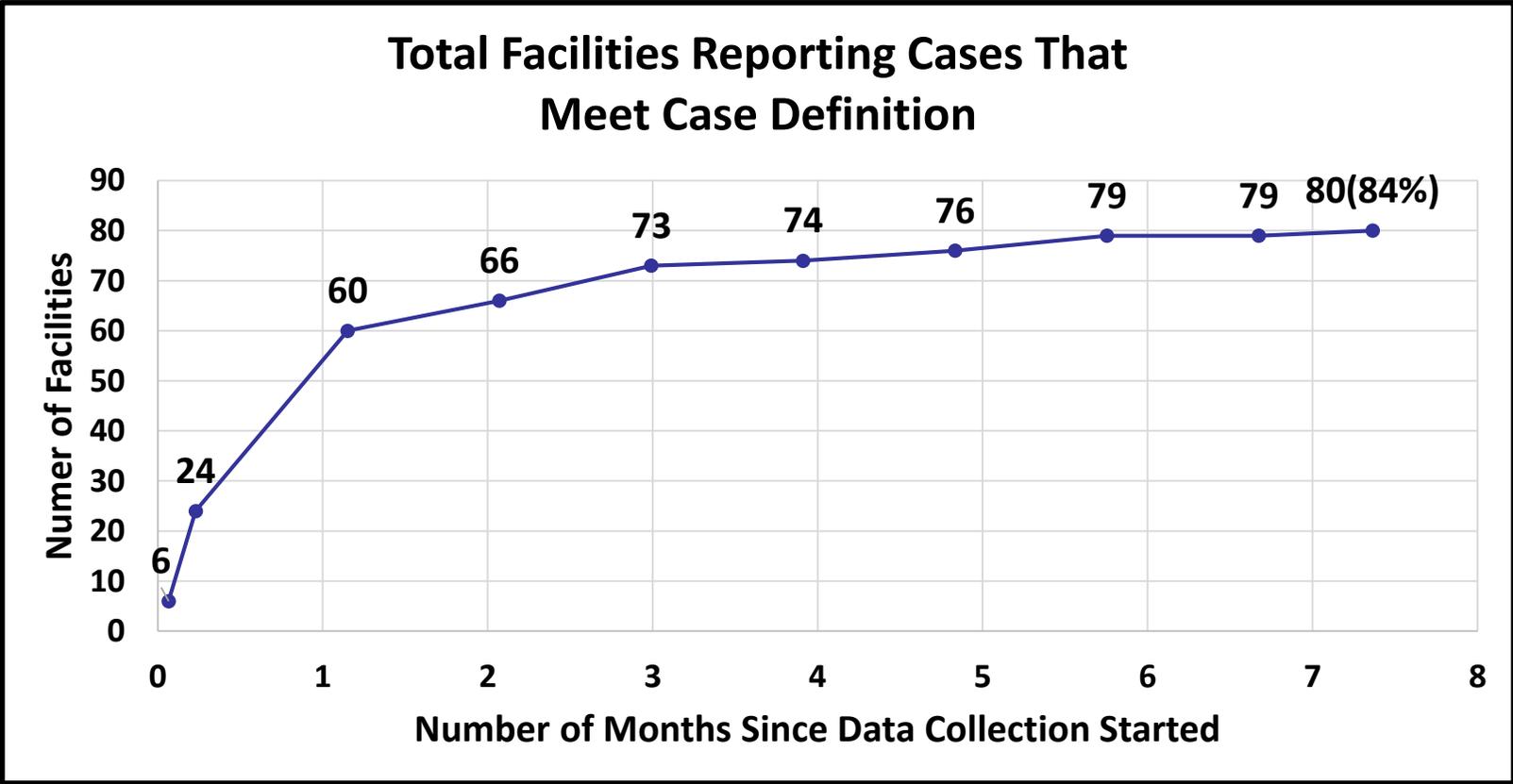
**Within two days, 18 cases were reported from six facilities**



State of emergency has been renewed twice, each time for an additional 90-day period.

Two facilities added to original list, totaling 95.

# NAS Data Collection: Number of Facilities



State of emergency has been renewed twice, each time for an additional 90-day period.

Two facilities added to original list, totaling 95.

# Neonatal Abstinence Syndrome (NAS) Data Summary

		NAS (2018)			PA 2016 live births	
		Total Responses	n	%	n <sup>1</sup>	%
<b>Total NAS Cases</b>		<b>1201</b>	<b>1201</b>	<b>(100%)</b>		
<b>Maternal</b>						
Race	Identified as White	1201	1029	<b>86</b>	97,939	<b>70</b>
Prenatal Care	Any known prenatal care	1171	1008	<b>86</b>	137,227	<b>98</b>
Payment Source	Principle source = Medicaid	1201	984	<b>82</b>	225,034*	<b>32*</b>
<b>Infant</b>						
Birth Weight	Less than 2500 grams at birth	1187	232	<b>20</b>	11,375	<b>8</b>
Gestational Age	Less than 37 weeks	1187	184	<b>15</b>	12,951	<b>9</b>
Level of Care	Received care in a NICU	1201	564	<b>47</b>		
Symptoms	Displayed 3 or more NAS symptoms	1201	1123	<b>94</b>		

# NAS Data Summary—Laboratory Testing

		n	%
<b>Total Number of NAS Cases Reported</b>		<b>1201</b>	<b>100</b>
<b>Laboratory Evidence of Exposure in Infant</b> <i>(Missing=30)</i>		<i>1171</i>	<i>(100%)</i>
<b>Test Results</b>	<i>Tested positive</i>	<b>780</b>	<b>67</b>
	Tested negative	<b>146</b>	<b>12</b>
	Pending	<b>130</b>	<b>11</b>
	Not Tested	<b>115</b>	<b>10</b>
<b>Among Total Number of Infants Testing Positive</b>		<b>780*</b>	<i>(100%)</i>
<b>Type of Opioid Detected</b>	Some form of opioids	<b>663</b>	<b>85</b>
	Medications used to treat substance use (methadone, buprenorphine)	<b>522</b>	<b>67</b>
	Oxycodone, fentanyl, other opiates or synthetic opioids	<b>180</b>	<b>23</b>

\*Categories not mutually exclusive

“Medications used to treat substance use” category may also include illicit use of these drugs

# NAS Data Summary—Infant Treatment

<b>Infant Treatment</b>	<b>n</b>	<b>%</b>
<b>Total Number of NAS Cases Reported</b>	<b>1201</b>	<b>100</b>
<b>No treatment</b>	<b>359</b>	<b>30</b>
<b>Morphine</b>	<b>531</b>	<b>44</b>
<b>Nonpharmacologic treatment</b>	<b>311</b>	<b>26</b>
<b>Other pharmacologic treatment</b>	<b>131</b>	<b>11</b>

Categories not mutually exclusive

# NAS Data Collection

## ➤ Other Initiatives

- Distributed guidance with authority to report, case definition, and exclusion criteria—in one notification
- Collaborated with The Hospital & Healthsystem Association of Pennsylvania (HAP) advocacy organization
- Created ‘Frequently Asked Questions’ document
- Included ‘Comments or Questions’ box within survey
  - ▣ Aid data collection and communication



# Challenges

## Case Definition

- No nationally standardized case definition for public health surveillance!

## Little Time for Reporter Education

- 'Reporting' case definition vs. within-facility diagnosis criteria
- Reporting timeframe

## Limited Resources for Continuous Facility Outreach

- Understanding barriers for non-reporters
- Maintaining continuous facility participation

# Successes Leading to Data Preparedness

## Built Capacity

- Leveraged infrastructure and the experience gained from the one-time supplemental Zika funding

## Maintained State Momentum

- During declaration of emergency, collected large amounts of clean data in a short period

## Provided Precedent

- Proved a viable method for collecting data on emerging threats

# Next Steps for Pennsylvania

## Data Preparedness Model:

Rapid demographic and clinical data leads to detailed next steps

### ➤ CDC Epi-Aid Assistance

- Survey facilities to assess barriers to reporting
- Identify varying case definitions and barriers to diagnosis
- Evaluate data validity



# Next Steps for Pennsylvania

- **Make NAS reportable beyond the declaration**
- **Consider adding NAS to newborn screening module**
- **Discuss with partners:**
  - Department of Human Services: Office of Children, Youth and Families
  - Department of Health: Bureau of Family Health
    - ❑ Engaged in survey that will evaluate facilities' current testing and diagnosis methods, and current policies and procedures
    - ❑ Collaborating on public health actions and guidance, including the development of plans of safe care in compliance with the Child Abuse Prevention and Treatment Act (CAPTA)



# Emerging Health Threats: How Surveillance Can Inform Clinical Practice



**Dana Meaney-Delman, MD, MPH**

*Acting Branch Chief, Prevention Research and Translation Branch*

Division of Congenital and Developmental Disorders

National Center on Birth Defects and Developmental Disabilities, CDC

# Protecting Pregnant Women and Infants: A Personal Story

Clinical Practice



Public Health Surveillance



Clinical Guidance

Centers for Disease Control and Prevention  
**MMWR**

Morbidity and Mortality Weekly Report

Early Release / Vol. 65

January 19, 2016

**Interim Guidelines for Pregnant Women During a Zika Virus Outbreak — United States, 2016**

Emily E. Petersen, MD<sup>1</sup>; J. Erin Staples, MD, PhD<sup>2</sup>; Dana Meaney-Delman, MD<sup>3</sup>; Marc Fischer, MD<sup>2</sup>; Sascha R. Ellington, MSPH<sup>1</sup>; William M. Callaghan, MD<sup>1</sup>; Denise J. Jamieson, MD<sup>1</sup>

# Outcomes Related to Exposures during Pregnancy

**Surveillance data can identify outcomes associated with exposures during pregnancy**



## Maternal Outcomes

- Pregnancy loss
- Maternal morbidity
- Maternal mortality
- Lack of access to care



## Infant Outcomes

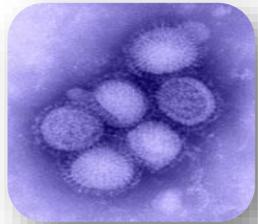
- Birth defects
- Preterm birth
- Small for gestational age/low birth weight
- Neonatal complications (e.g., NAS)
- Infant morbidity and mortality



## Child Outcomes

- Cognitive impairment
- Motor development
- Developmental delays
- Behavioral issues
- Educational attainment

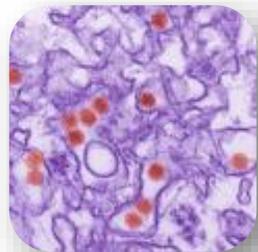
# Recent Public Health Emergencies



**2009 H1N1  
Influenza**



**2014  
Ebola**



**2016  
Zika**

## What did we learn?



**Pregnant women and infants may experience severe outcomes**

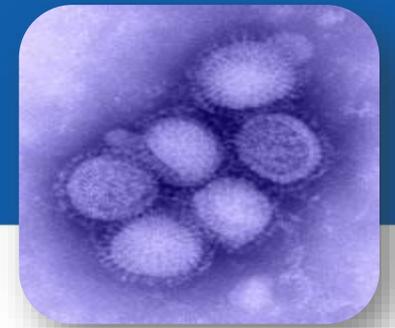


**Healthcare providers request guidance on infection control, prevention and treatment of emerging diseases**



**Rapid data collection can inform emergency response activities and new guidance**

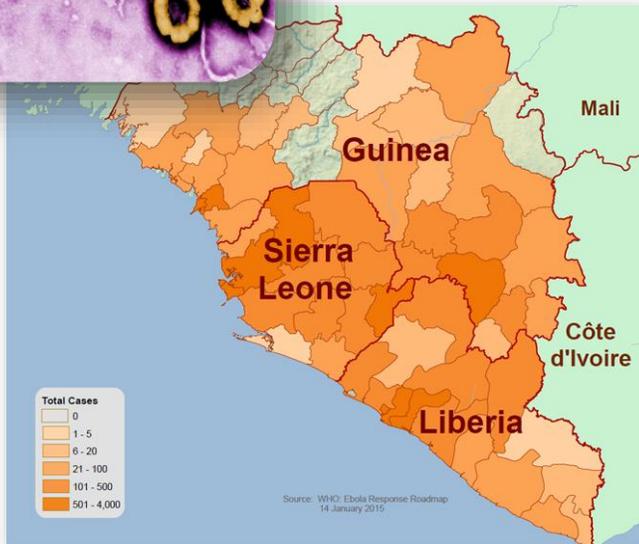
# Lessons Learned: H1N1 Influenza



- **Increased mortality**
  - 5% of all deaths were among pregnant women, who represent 1% of general population
- **Importance of treating pregnant women with influenza antiviral medications**
- **Challenges with vaccine acceptance**
- **Need for up-to-date scientific information during an evolving outbreak situation**
  - Pregnancy flu-line: Surveillance and clinical hotline



# Lessons Learned: Ebola



- High rates of pregnancy loss, maternal and neonatal death
- Unclear if women disproportionately affected or higher rates of maternal mortality
- OB wards served as points of transmission
  - Viral shedding in amniotic fluid and placenta
- Recommendations needed for labor and delivery setting

# Lessons Learned: Zika Virus



**Zika causes serious brain abnormalities**



**Pattern of birth defects:  
congenital Zika syndrome**



**5-10% risk of birth defects from congenital infection**

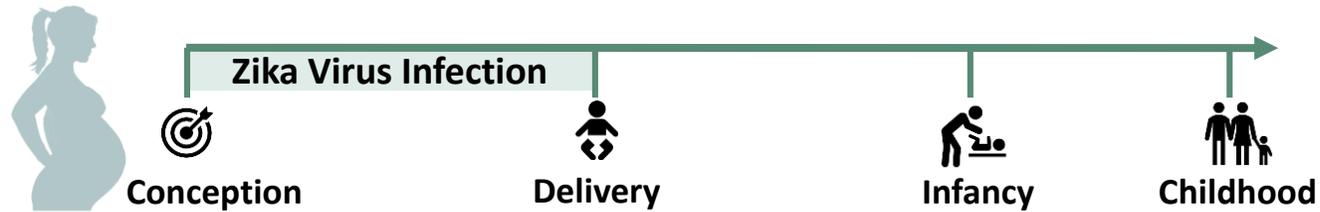


**Zika infection during any trimester associated with birth defects**

# Zika Pregnancy and Infant Surveillance: Data for Action

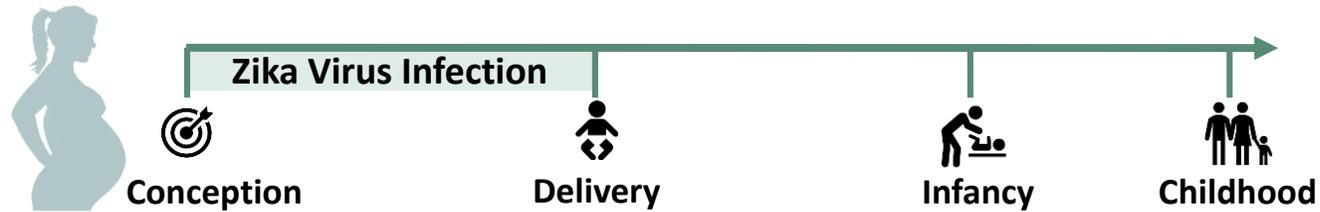
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## U.S. Zika Pregnancy and Infant Registry



# Zika Pregnancy and Infant Surveillance: Data for Action

## 1 U.S. Zika Pregnancy and Infant Registry

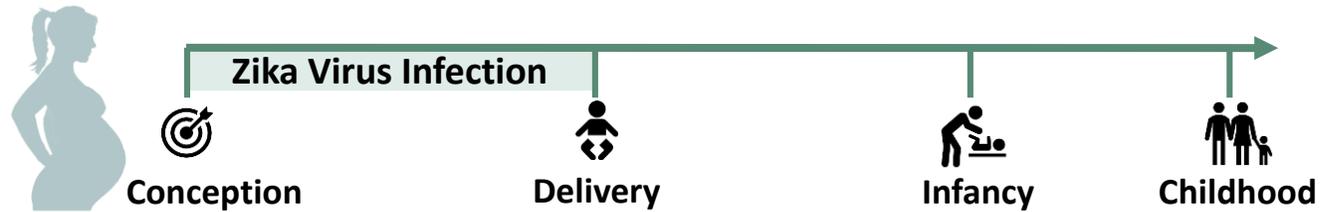


## 2 Birth Defects Surveillance

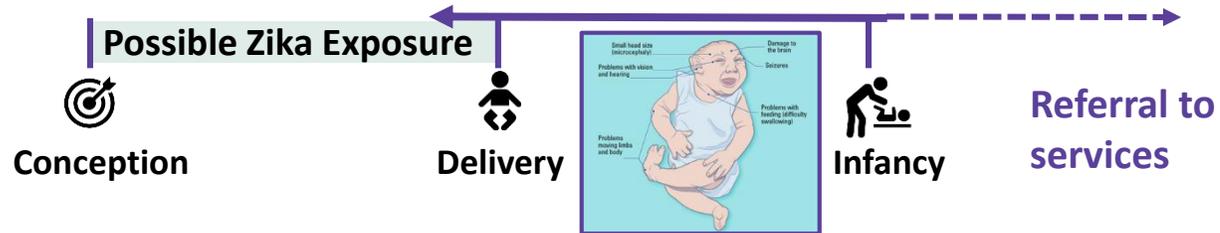


# Zika Pregnancy and Infant Surveillance: Data for Action

## 1 U.S. Zika Pregnancy and Infant Registry



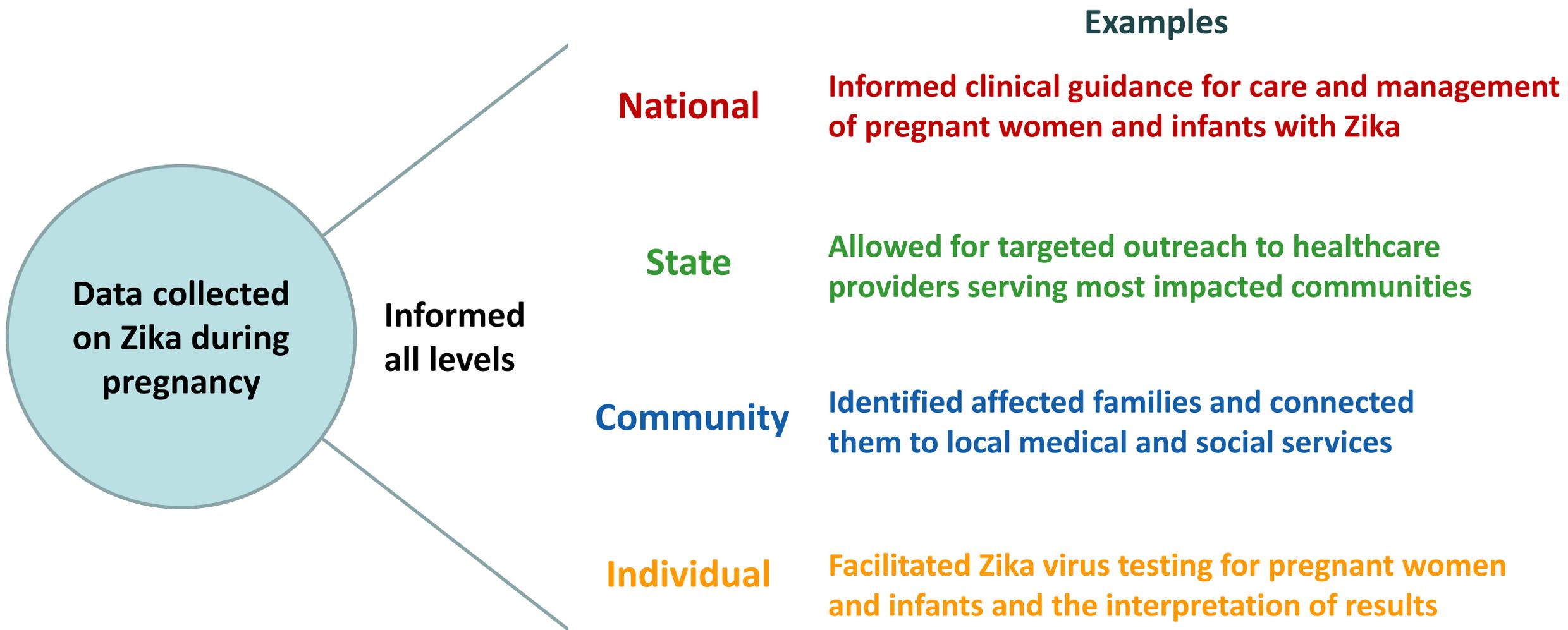
## 2 Birth Defects Surveillance



## 3 Health Department Surge Capacity

## 4 U.S. Zika Pregnancy Hotline

# Benefits of Surveillance Data

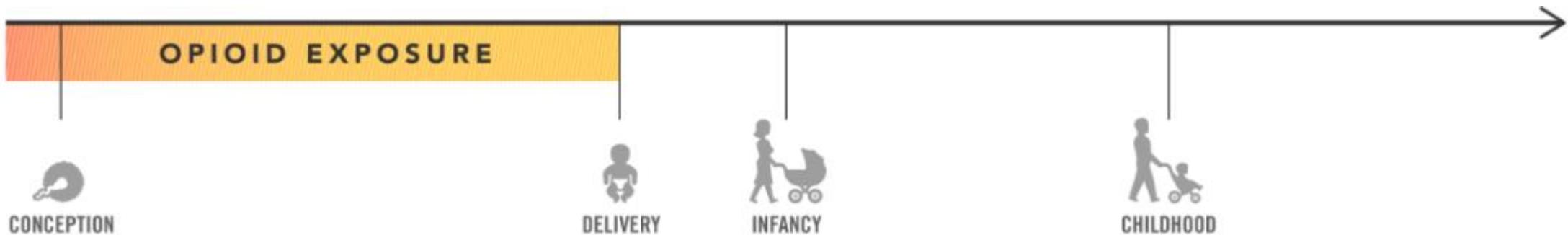


# Applying Lessons Learned to Other Pregnancy Exposures



## Maternal Outcomes

- Pregnancy loss
- Maternal morbidity
- Maternal mortality
- Prolonged hospital stay
- Lack of access to care

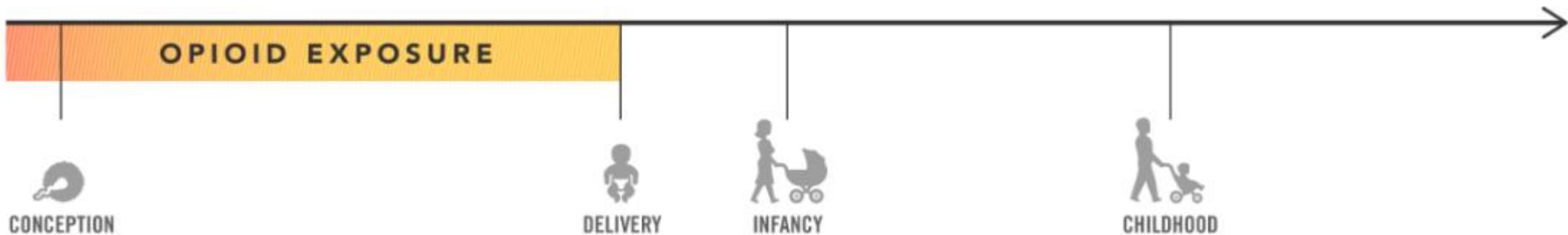


# Applying Lessons Learned to Other Pregnancy Exposures



## Infant Outcomes

- Birth defects?
- Preterm birth
- Small for gestational age/low birth weight
- Neonatal complications (e.g., NAS)
- Prolonged hospital stay
- Infant morbidity and mortality

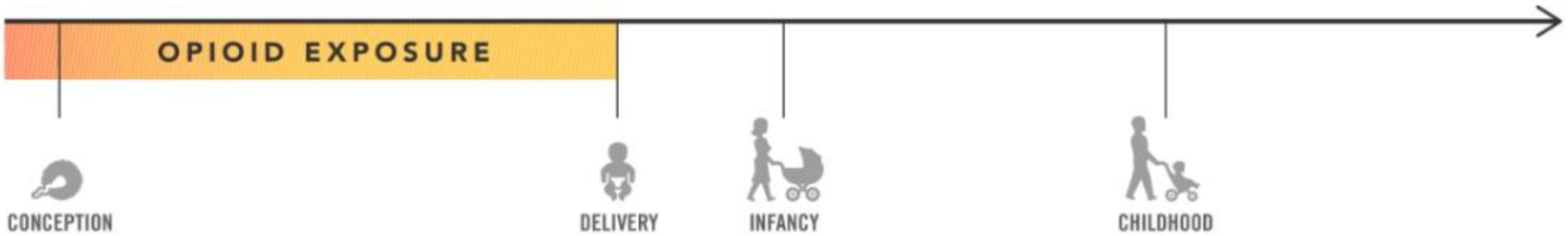


# Applying Lessons Learned to Other Pregnancy Exposures



## Child Outcomes

- Cognitive impairment
- Motor development delays
- Developmental delays
- Behavioral issues
- Educational attainment
- Family dynamics



# Surveillance for Emerging Threats NETWORK (SETNET)

**Pregnancy  
and Infant  
Surveillance  
System  
to monitor  
health threats**

- 1** Monitor mothers and children with exposures during pregnancy
- 2** Adapt birth defects surveillance to rapidly monitor associated outcomes
- 3** Provide health department surge capacity
- 4** Provide ongoing assistance to healthcare providers

# Common Themes: Common Needs

- **Longitudinal surveillance of mother and infant dyad**
- **Routine capture of pregnancy status**
- **Collection of real-world, timely data to inform the best care for mothers and infants**
- **Standard case definitions**
- **Access to and linkage of multiple data sources**
- **Outreach and education**

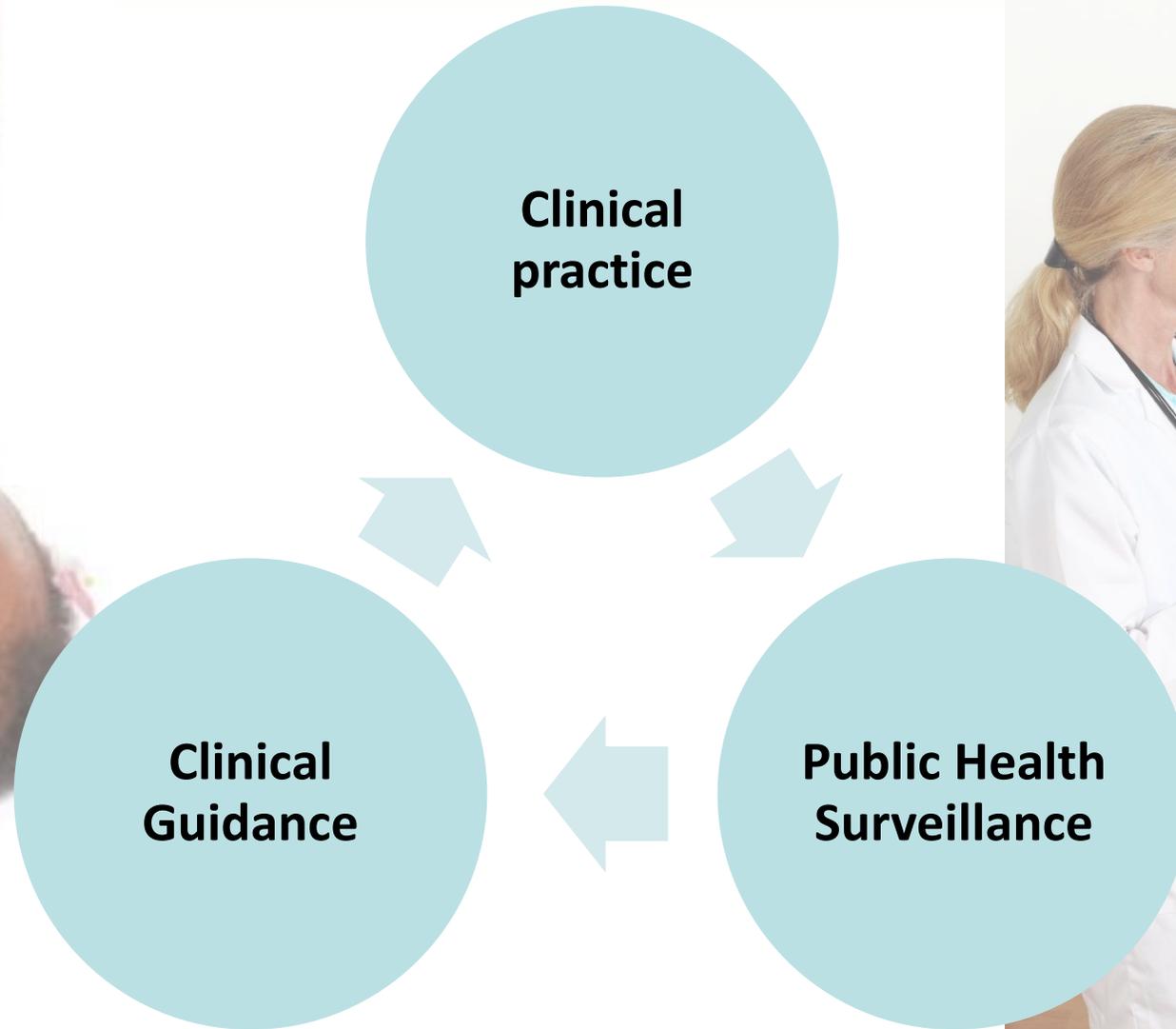


# Common Themes: Common Challenges

- **Inconsistent case definitions hinder comparing and combining data**
- **Identifying exposed pregnant women**
- **Lost to follow up**
- **Unknown long-term outcomes**
  - How will children exposed prenatally thrive as they grow?
  - What services and support will they need?



# Pregnancy and Infant Surveillance: Data to Action



# A Call to Action

**A sustained and consistent approach to surveillance for pregnant women and infants can ensure public health and clinical communities:**

- Act early to protect mothers and babies
- Identify maternal risks (e.g., morbidity and mortality) and childhood risks (e.g., birth defects, health problems, developmental delays, and functional disabilities)
- Inform prevention strategies and clinical management
- Link affected families to medical and social services

