Highlights from CDC's National Center on Birth Defects and Developmental Disabilities

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AUCD JOINT DIRECTORS MEETING PANEL

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SAVING BABIES

HELPING CHILDREN

PROTECTING PEOPLE

IMPROVING HEALTH

SAVING BABIES

Through Birth Defects Prevention and Research

New Funding Opportunities for FY16

- Autism: Study to Explore Early Development (SEED) – Phase 3
  - $27M to 6 sites
- Zika Funding
  - Over $20.5M to 50 grantees
  - Priority areas funded based on potential for local mosquito-borne transmission of Zika virus

Anticipated Funding Opportunities for FY17

- Surveillance, intervention, and referral to services activities for infants with microcephaly or other adverse outcomes linked with the Zika virus
  - State FOA: Over $16M to 35 states, 5 territories
  - High risk local areas FOA: Over $2.3M to 4 cities, 1 county
- Population-based surveillance of birth defects and data utilization for public health action
  - Over $2.7 to 13 states, 1 territory

HELPING CHILDREN

Live to the Fullest by Understanding Developmental Disabilities

Major Accomplishments from FY16

- Learn the Signs. Act Early. (LTSAE)
  - Milestones photo/video library
  - Soft Book Launch - “Where’s Bear? A Terrific Tale for 2-year-olds.”
- Autism Awareness Event with Ed Asner

Future Directions for FY17

- LTSAE Developmental Milestones App

HELPING CHILDREN

Live to the Fullest by Understanding Developmental Disabilities

Major Accomplishments from FY16

- Launched “Physical Developmental Delays: What to Look for” tool
- Released Fragile X (FXS) Myth Buster handout
- Released CDC Vital Signs: ADHD in Young Children: Use Recommended Treatment First

Future Directions for FY17

- Upcoming publications
  - Fragile X Supplement in Pediatrics- care of individuals with Fragile X.
  - MMWR on Children’s Mental Health in Rural Settings

IMPROVING HEALTH

Improving the Health of People with Disabilities

New Funding Opportunities for FY16

- Improving the Health of People with Mobility Limitations and Intellectual Disabilities through State-based Programs; $5.4M to 19 states
- National Centers on Health Promotion for People with Disabilities; $6M

Anticipated Funding Opportunities for FY17

- Documentation and Use of Follow-up Diagnostic and Intervention Services Data through the Maintenance and Enhancement of the EHDI-IS; $6.9M to 42 states and territories.

First time in history…

"Never before in history has there been a situation where a bite from a mosquito could result in a devastating malformation."
– Dr. Tom Frieden, CDC Director
Fortune, April 13, 2016

"…the last time an infectious pathogen (rubella virus) caused an epidemic of congenital defects was more than 50 years ago…"
– *New England Journal of Medicine*, April 13, 2016

Where is Zika now?

Congenital Zika Syndrome

- Recently recognized pattern of congenital anomalies associated with Zika virus infection during pregnancy that includes
  - **Severe microcephaly** resulting in a partially collapsed skull
  - **Decreased brain tissue** with brain damage (as indicated by a specific pattern of calcium deposits)
  - **Damage to the back of the eye** with a specific pattern of scarring and increased pigment
  - **Limited range of joint motion**, such as clubfoot
  - **Too much muscle tone** restricting body movement

  soon after birth

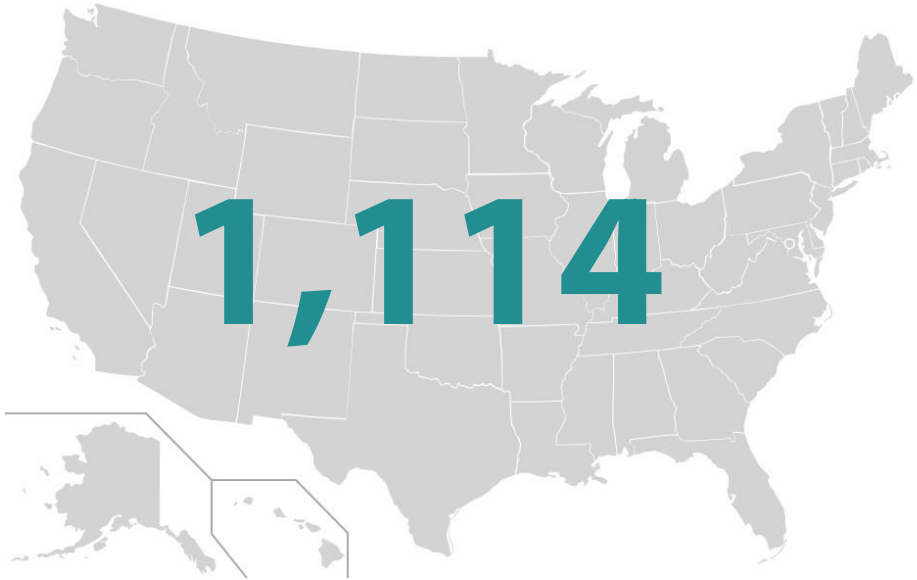
Baby with Severe Microcephaly

Potential Risk of Microcephaly

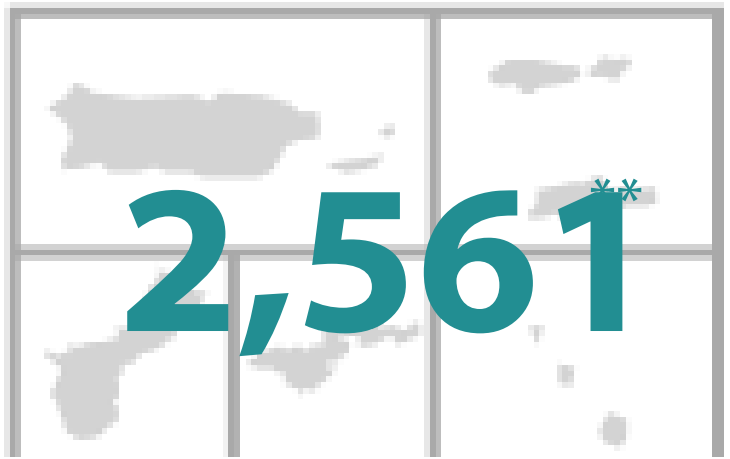
- **1 - 13%** estimated risk of microcephaly due to Zika virus infection in first trimester
  - Modeling based on current outbreak in Bahia, Brazil
- *Important to remember*
  - Data are limited (infection rates unknown; microcephaly cases still being reported)
  - Microcephaly is difficult to detect prenatally
  - Microcephaly is only one of a range of possible adverse outcomes

Johansson MA, Mier-Y-Teran-Romero L, Reefhuis J, Gilboa SM, Hills SL. Zika and the Risk of Microcephaly. N Engl J Med. 2016 May 25 [Epub ahead of print].

Number of Pregnant Women Who May Be Affected



Pregnant women with any laboratory evidence of possible Zika virus infection in the **50 US States and DC**



Pregnant women with any laboratory evidence of possible Zika virus infection in **US Territories**

*Includes aggregated data reported to the US Zika Pregnancy Registry as of November 17, 2016

**Includes aggregated data from the US territories reported to the US Zika Pregnancy and data from Puerto Rico reported to the Zika Active Pregnancy Surveillance as of November 17, 2016

Adverse Pregnancy Outcomes

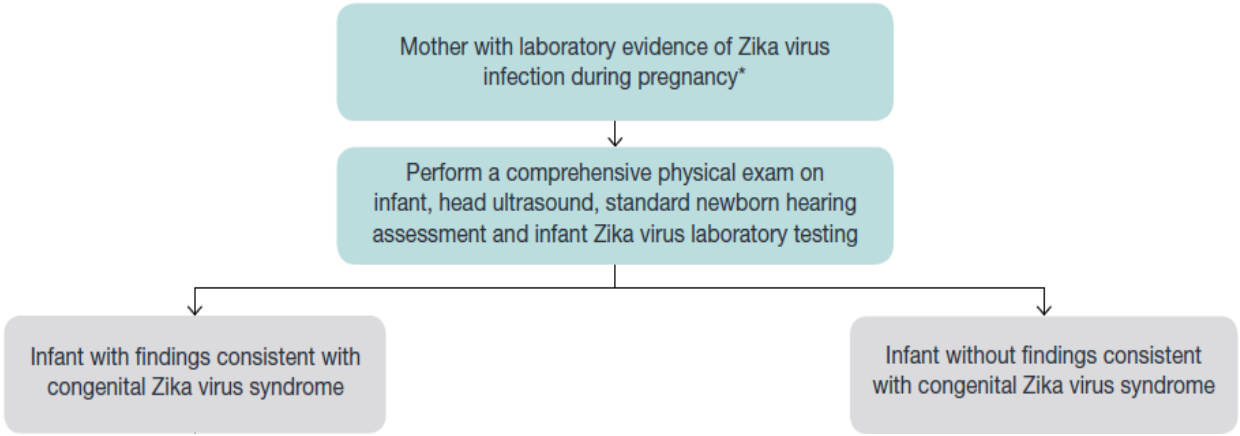
Pregnancy Outcomes in the United States and the District of Columbia

Liveborn infants with birth defects*	Pregnancy losses with birth defects**
28	5
Includes aggregated data reported to the US Zika Pregnancy Registry as of November 17, 2016	Includes aggregated data reported to the US Zika Pregnancy Registry as of November 17, 2016

* Includes microcephaly, calcium deposits in the brain indicating possible brain damage, excess fluid in the brain cavities and surrounding the brain, absent or poorly formed brain structures, abnormal eye development, or other problems resulting from damage to the brain that affects nerves, muscles and bones, such as clubfoot or inflexible joints, and confirmed hearing loss.
**Includes miscarriage, stillbirths, and terminations with evidence of the birth defects mentioned above

Infants with Possible Congenital Zika Virus Infection

- Testing of infants with possible congenital Zika virus infection should be guided by
  - Whether the infant has abnormalities consistent with congenital Zika syndrome
  - The mother's Zika virus testing results
- All infants should have a comprehensive physical exam and head ultrasound before discharge from the hospital regardless of the presence or not of abnormalities and prenatal ultrasound results



Link: http://www.cdc.gov/zika/pdfs/zika_peds.pdf

Guidelines for Caring for Babies with CZ exposure

Infants with abnormalities consistent with congenital Zika syndrome born to a mother with lab evidence of Zika

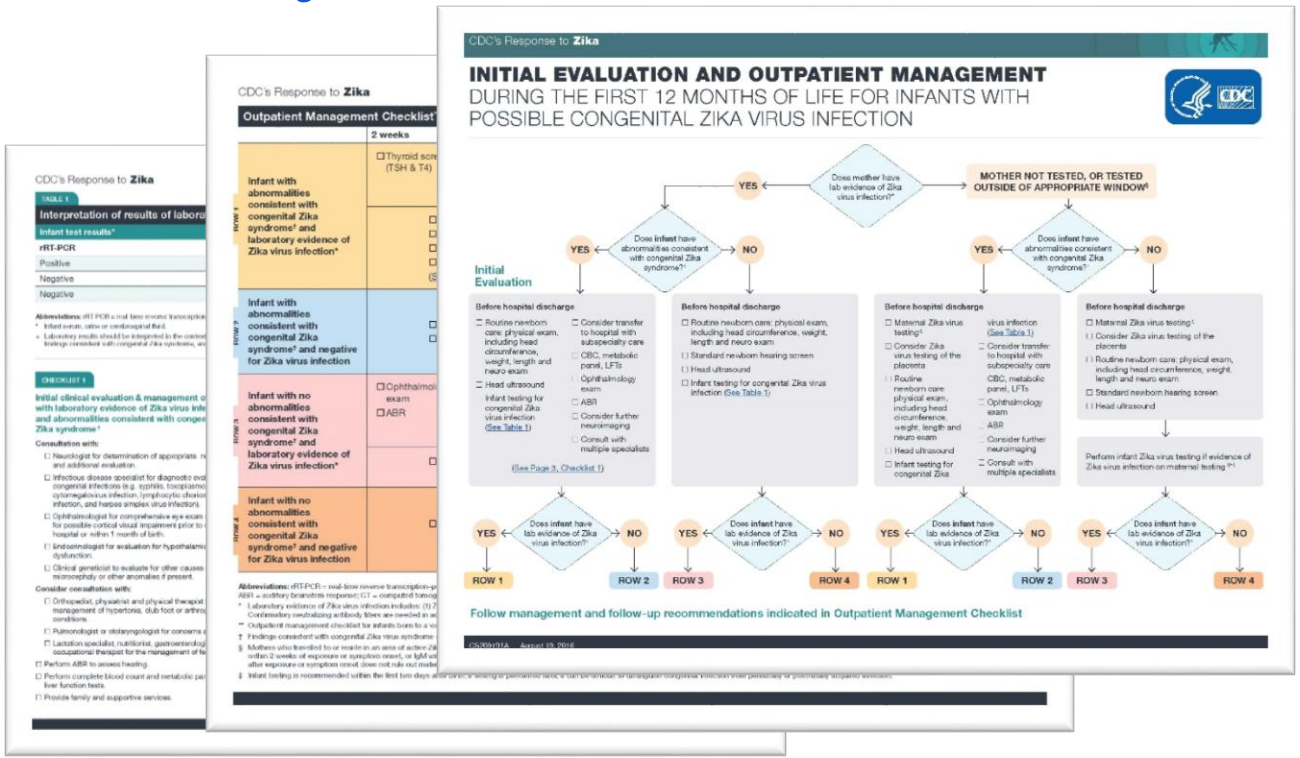
- Before hospital discharge:
  - ✓ Routine newborn care: physical exam, including occipitofrontal (head) circumference, weight, length, and a neurologic exam
  - ✓ Head ultrasound
  - ✓ Testing for congenital Zika virus infection
  - ✓ Complete blood count, metabolic panel and liver enzyme testing
  - ✓ Consult with multiple subspecialists
  - ✓ Comprehensive eye exam by an ophthalmologist
  - ✓ Auditory brainstem response (ABR) hearing evaluation
  - ✓ Consider advanced cranial imaging (e.g., MRI)
  - ✓ Consider transfer to hospital with subspecialty care

Family and Psychosocial Support

- Families and caregivers of infants with congenital Zika virus infection will require ongoing psychosocial support.
- Families should be empowered to be active participants in their child's monitoring and care.
- Healthcare providers should work closely with parents to ensure that the care plan is consistent with the infant's needs and the family's wishes.
- Families with already limited access to medical care might be affected with a disproportionate burden of Zika virus infection
- Barriers to care for all affected infants and their families should be addressed by linking them with national, state, and local health programs.
- Additional resources for families can be found at: http://www.cdc.gov/zika/parents/families-of-newborns-affected-zika.html

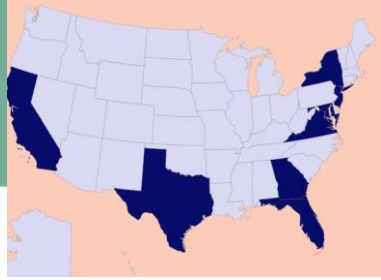
Pediatric Evaluation and Follow-up Tools:

Initial Evaluation and Outpatient Management During the First 12 Months of Life for Infants with Possible Congenital Zika Virus Infection



Download at:
http://www.cdc.gov/zika/pdfs/pediatric-evaluation-follow-up-tool.pdf

Improving Access to Clinical Services for the Management of Zika Virus



Assessment

Identify factors that may influence access to clinical services

Ongoing-January 2017

Implementation

Establish Provider Network in 10 high-risk jurisdictions

April 2017

Evaluation

Track Website and HelpLine usage

July 2017

Thank you